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ABSTRACT

This community home care program for family caregivers is designed to provide information to family caregivers on ways to provide care more easily in the home by making changes in the home, and drawing on resources from outside the home. It provides guidelines for volunteer "hosts," i.e., persons who coordinate and run the course, on how to assist family caregivers in making important decisions for themselves or their loved ones. These topics are discussed: (1) the decision to host this program; (2) information for the host, such as creating a calendar, publicity for the program, and evaluation of the program; (3) detailed outlines for the host on nine modules including personal care, finances, home environment, mobility, medications, and family interactions; (4) information for caregivers, such as directions for using the caregiver questionnaire and a program overview for the caregiver; and (5) information for guest presenters, including tips for group facilitation, discussing emotions with caregivers, and outlines for the presenters for each of the modules. Two optional resource booklets for use with this program are listed at the conclusion of the manual. (ABL)

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ED315676

Home Is Where the Care Is

A Community Course

CG022255

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Foreword

Through its Women's Initiative, AARP has made a commitment to assuring availability, accessibility, and quality of long-term care. Recognizing that women generally live longer than men and are, therefore, both providers of care for others and particularly vulnerable themselves to chronic conditions requiring long-term care, AARP has undertaken to provide information that will permit informed decision making to meet individual changing needs.

This community home care program for family caregivers represents part of a comprehensive consumer education effort in the area of long-term care. It is designed to provide information to family caregivers, the majority of whom are women, on ways of providing care more easily in the home through changes made in the home, and resources that can be drawn on from outside the home. The program is intended to provide guidelines for assisting family caregivers in making important decisions for themselves, or their loved ones and as a result, help them become better consumers.

This program has been developed by AARP and is intended solely for use in its present form. Unauthorized use of this AARP program for commercial purposes is prohibited and may result in legal action.

With more than 26 million members, the American Association of Retired Persons is the nation's largest nonprofit, nonpartisan organization of Americans age 50 and older. AARP offers a wide range of membership benefits, legislative representation at federal and state levels, and educational and community service programs which are implemented through a national network of volunteers and local chapters.

Written by
Karalee T. German

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Introduction

"Home Is Where the Care Is" is a guide for the preparation and presentation of a training course for persons who care for a chronically ill, disabled, or frail older person at home. It has been designed by the American Association of Retired Persons (AARP) in response to the growing number of persons who are being cared for at home and to the needs of the person to whom responsibility for this care falls. This person is a family caregiver; the person receiving care is the care recipient.

AARP conducted extensive interviews with randomly selected caregivers and care recipients; in addition to discovering problems unique to specific situations, we discovered problems that many caregivers shared. Foremost, we found that most family caregivers were thrust into very difficult physical and emotional situations for which they were unprepared. We also interviewed professionals committed to helping caregivers. From all these interviews we learned about many techniques, resources, and products that most caregivers can put to immediate use to make their jobs easier. This training course is the direct result of these studies.

"Home Is Where the Care Is" is designed for implementation in small community groups. This program packet includes planning and presentation guidelines and master copies of materials that may be reproduced or ordered in the needed quantities. The group, or groups, sponsoring this course will provide the person who is most important to this course - - a coordinator, or the one referred to as the host; that is, the person who puts it all together and runs the course. Although the host should be familiar with caregiving, he or she does not have to be an expert in the subjects covered by the course; professionals in the community who are experts probably will agree to conduct parts of the course when asked. These people are guest presenters.

There are a few key tasks that fall to the host, or someone recruited by the host, to do. These include publicizing the course, identifying and arranging for guest presenters, assisting in arrangements for caregivers who need respite care to attend the course, arranging for meeting facilities, and overseeing the actual classes.

Caregiving is not new. What is new are the demands and stresses being placed now on family caregivers who are themselves more often part of the older population. Some of those stresses come from the fact that many caregivers add the responsibilities of providing care to others such as managing the home, caring for other family members, and maybe even holding a full- or part-time job. Other stresses in caregiving are due to the complexity of the care now required at home - - care that would have dictated hospitalization in times past. This course is designed to lessen the stress on family caregivers by broadening their view of support and aids available to them. From the host of this program and the guest presentations, caregivers will learn about providing personal care, creating a safe and efficient home environment, managing nutrition, medication, financial and legal issues, and utilizing community resources. In addition, caregivers will have an opportunity to share valuable suggestions based on their own experience, and express difficult emotions in a supportive and understanding group. Using this program material, the host can assist family caregivers in the community by reinforcing the idea that they are not alone in their caregiving role, by providing them with ideas and techniques they can put to immediate use, and by leaving the caregivers with means to get more information as necessary. AARP hopes you will find this program material to be a valuable asset to your community.

Goals of Program

The goals of the program are to:

- Convey practical information to the caregiver
  - Provide immediately useful information in a concise format;
  - Boost caregiver's confidence in providing care by reinforcing other training that he or she might have received;
- Encourage the independence of the care recipient;
- Emphasize the need for the caregiver to take care of himself or herself;
- Make sure the caregiver realizes that he or she is not in the caregiving situation alone
  - In spirit, through the support of others involved in this program;
  - In fact, through an awareness of relevant resources available;
- Leave the caregiver with a better way of coping when this course ends
  - Give examples of ways to provide care creatively;
  - Help the caregiver access community and written resources.

Format of Program

This nine-module program is presented in outline format to encourage an informal presentation of material, as opposed to a lecture presentation. The informality should promote sharing and discussion among the host, the guest presenter, and the caregivers in attendance. The program host, or guest presenter, should cover all the points listed in the outline, in addition to comments based on personal experience. The outlines are very detailed but AARP feels that is what caregivers are looking for. They need specific ideas and information. This will be borne out by the questions caregivers will ask in addition to all the information provided by this program material.

On the assumption that most caregivers will be involved in this program when they need it, rather than in anticipation of needing it, the program has a minimal number of handouts that might burden the caregiver during an already stressful time. When this program is presented in a caring and supportive way, the information relevant to each caregiver will be remembered by that person. A sample of an AARP (turquoise) Additional Resources booklet is included in this program material. You may want to order copies of it or have on hand other resources you know to be helpful. However, we urge you not to inundate the caregivers with handouts they may feel guilty about not reading. Rather, provide ordering and/or locating information (such as the AARP booklet) for reading materials and other resources for the caregiver who has the time and inclination to go into a subject in more depth.

Format of Modules

This program material is organized into nine two-hour modules, the last module of which is optional.

Organizational material for the first eight modules includes:
- Preparation guide for the host
  - Goals of the particular module
  - Checklist of things to do
  - Suggested community source(s) for guest presenter(s)
  - Suggested handouts for caregivers
- Preparation guide for the presenter
  - Goals of the particular module
  - Subject matter to be covered.

The first eight modules have a similar agenda:
- Time for informal sharing among caregivers;
- Time for presentation of program material;
- A short break during the presentation to stretch, and for healthful refreshments;
- Wrap-up with time for formal and informal sharing.

Although it may appear that a large portion of the two hours is planned for sharing among the caregivers, that time is quite valuable both for the exchange of firsthand information among caregivers, and for allowing the caregivers a crucial opportunity to express feelings and be listened to.

Neither the topic nor the agenda of the optional ninth module is set. Some topics are suggested, but the content and agenda should be tailored to meet the needs of the specific caregivers based on an assessment provided for in this program material.

Order of Modules

The modules have been ordered both by subjects that seem to go well together and by the amount of time each subject within a module is expected to take. The first module is on personal care in the hope that the caregiver, picking up at least one great idea to implement immediately at home, will leave the first session aware of the personal value to himself or herself of attending the remaining sessions. Community resources, in some ways the most important module, is second. It is too overwhelming to offer in the first session when caregivers are just getting used to the idea of changing some of the ways they have been doing things. It should be offered early in the course, however, so the caregiver can begin to use the resources while still in the supportive environment of Home Is Where the Care Is. The module on legal and long-range planning follows the financial module, rather than being coupled with it, only because there is not enough time to cover them both in one module.

Although emotions are discussed in each of the modules relative to the main subject, having the emotions of the caregiver and care recipient as the key subject of a module is the eighth and last regular module for several reasons. Since the subject of emotions is probably one of the most important subjects, the eighth module allows time for going back to emotional issues that were not adequately addressed in earlier modules, or that may have been skipped due to lack of time. The eighth module allows for wrap-up, or closure, of the program within the context of the emotional aspect of caregiving. The greater amount of sharing among caregivers in the eighth module should also leave them, in their last two formal hours together, with a clear feeling that they are not alone or without help in a difficult situation.

Group Size

It is hoped that the host will keep program participation to between 10 and 20 caregivers. With a group of that size:

- The host may have a better chance of lining up respite care for caregivers who need it in order to attend the course;
- All the caregivers will still be able to participate in the limited time available for discussion, and the demonstration and practice sessions;
- Questions and answers can be very specific to the needs of each caregiver;

- There will be maximum opportunity to get to know and care about one another during the program, and to explore the possibility of continuing informally after the program as a support group.

Program Timetable

There is no specific timetable for presenting this program. That is left to the individual program host. Variables that might need to be considered when deciding how many sessions to have in a week, and what time of day to schedule them, are:

- When caregivers are free to attend the program because of available respite care;
- The time of year which might impact on driving to the program in daylight or darkness;
- When the chosen program site is available;
- What major holidays will fall in the schedule, etc.

The two-hour modules may be presented one or two per week, three per day in seminar fashion, or however it will work best for the participants involved. If the modules are run two or more at a time the total time may be a bit less than two hours per module from combining some of the discussion time.

Cost of Program

The following areas may involve some expense if donations cannot be obtained:

- Advertising the program;
- A meeting room in which to hold the program;
- Refreshments to serve at each meeting;
- Rental of film, projector;
- Duplication of handouts (copies ready for reproduction are included in this program packet).

Renting the film recommended in this material will cost $40. All other costs are best calculated by the host. It is assumed that guest presenters would be either volunteers or working on donated professional time.

Host Organizations

An organization that might host this program for caregivers needs:

- Experience in assisting caregivers;
- Experience in small group process;
- One person who can coordinate the entire program and lead each module;
- Access to professionals who can speak knowledgeably to the caregivers on the topics covered in the program modules:
    - Persons from within the organization itself;
    - Access to persons from the community who can be invited to make presentations.

Examples of such organizations include:

- Hospitals
- Area Agencies on Aging
- Adult day care centers
- Senior citizen centers
- Nursing homes
- Schools of gerontology
- Religious organizations
- Home care agencies
- Cooperative extension offices
- Family service agencies
- Mental health centers.

Host Individuals

NOTE: The host individual does not need to be from the sponsoring or cooperating organizations; in fact, the ideal situation would be for the host to be an independent volunteer from the community who could then gain more cooperation from all the supporting agencies that have speakers and resources to contribute.

An individual who might host this program for caregivers needs:

- Personal experience in caregiving and utilizing community resources;
- Experience in the dynamics of leading small groups;
- The time to coordinate the entire program and lead each module;
- Access to professionals in the community who can be invited to speak on the topics which the host is not prepared to speak on.

Examples of such an individual might include:

- A retired health professional;
- Someone who has recently been a full-time family caregiver.

Responsibilities of Host

The following is a summary of responsibilities to present "Home Is Where the Care Is" for caregivers in your community.

KEY ROLE OF HOST

- Be overall coordinator of program;
- Be familiar with the material in and requirements of each module.
- Attend each module to assure continuity and a smooth-running program.

BEFORE THE PROGRAM BEGINS

These tasks may be either completed by the host or delegated to another responsible person or organization:

- Publicize the program;
- Make logistical arrangements for meeting space;
- Identify and prepare guest presenters for any module topic on which the host will not be making the presentation;
- Assist in arranging respite care for caregivers who need it;
- Arrange for refreshments, handouts, and other resources for each module.

DURING THE PROGRAM

The host should:

- Provide opening and closing for each module;
- Time guest presentations;
- Be watchful of the involvement and feelings of the caregivers:
  - Be sensitive to the needs of both the caregivers and the care recipients;
  - Divide the available discussion time between factual information and the emotions the caregivers may be feeling;
  - Promote good small-group dynamics:
    - Make people feel comfortable;
    - Facilitate listening and expression;
    - Ensure everyone a chance to be involved;
    - Be flexible enough for a conversation to follow an unexpected twist if it is obviously important to the caregivers, without totally losing the subject at hand;
  - Be relaxed and reassuring; allow humor to surface for and among the caregivers;
- Be prepared to work into the outline any unique resources available in the community such as audiovisuals available from the county library (be sure to preview first), model outreach programs, university offerings, etc.

If You Decide to Host This Program

The detailed instructions included in the next section (Information for Course Host), will allow you to offer a valuable service to family caregivers in your community. It will be work, and it will take time, but you will be rewarded with the gratitude of the family caregivers you have helped.

Creating a Calender

You should set up a calendar dedicated solely to planning this program. Begin with a schedule for obtaining support from other persons and organizations. When you are ready to establish dates for the program modules, mark them on the calendar. Then working back from the date of each module write in on the calendar the tasks to be done in preparation for each one. A calendar example, based on presenting two modules per week, is on the following pages. For details on tasks to organize the program, turn to page 14.

SAMPLE Host's Schedule for Month 1

Sun	Mon	Tue	Wed	Thu	Fri	Sat
					Receive "Home Is Where the Care Is" material from AARP.	
	Read the entire course; make list of potential cooperating organizations.	Invite potential cooperating organizations to planning meeting next Wed.		Make list of publicity targets by monthly, weekly, daily categories.		
			First meeting of potential cooperating organizations.	Compile resources from cooperating organizations; reserve room beginning 1st Monday of month 3	Order 30 copies of safety checklist (Mod 3) & SSA Medicare booklet (Mod 5).	
	Confirm respite care resources in case they are needed for caregivers to attend course.	Confirm phone line for course information and registration.	Complete publicity information and hand deliver;last day to register is in four weeks.	Order any materials desired from AARP.		
	Schedule guest presenters for Modules 1-4; mail information to them.					

SAMPLE Host's Schedule for Month 2

Sun	Mon	Tue	Wed	Thu	Fri	Sat
	Contact guest presenters for Modules 1-4 to confirm and clarify roles.	Begin preparation of community resources booklet.	Schedule guest presenters for Modules 5-8; mail information to them.			
	As caregivers register, mail them information and return envelope.	Request film for Module 3.		Contact guest presenters for Modules 5-8 to confirm and clarify roles.		
			Final day to register for program.			
	Contact caregivers who have not returned forms yet; confirm plans to attend.		All information back from caregivers and compiled.		Mail reminder and caregiver profiles to Module 1 guest presenter.	
	Confirm respite care plans for caregivers who need it.	Mail reminder and caregiver profiles to Module 2 guest presenter.				

SAMPLE Host's Schedule for Month 3

Sun	Mon	Tue	Wed	Thu	Fri	Sat
			Confirm meeting room logistics for Module 1.	Duplicate any handouts for Modules 1-4.	Mail reminder and caregiver profiles to Module 3 guest presenter.	
	Prepare snacks; host Module 1.	Mail reminder and caregiver profiles to Module 4 guest presenter.		Prepare snacks; host Module 2; confirm film projector and operator for Module 3.	Mail reminder and caregiver profiles to Module 5 guest presenter & thank yous for Mod 1 & 2.	
	Prepare snacks; host Module 3; schedule guest presenter(s) for Module 9.	Mail reminder and caregiver profiles to Module 6 guest presenter.	Duplicate any handouts for Modules 5-8.	Prepare snacks; host Module 4.	Mail reminder and caregiver profiles to Module 7 guest presenter & thank yous for Mod 3 & 4.	
	Prepare snacks; host Module 5.	Mail reminder and caregiver profiles to Module 8 guest presenter.		Prepare snacks; host Module 6.	Mail thank you notes to guest presenters for Modules 5 and 6.	
	Prepare snacks; host Module 7.			Prepare snacks; host Module 8; mail thank you notes for Modules 7 & 8 & site contact.		

Cooperating Organizations

Enlist support for this program from organizations in your community. Call a meeting, explain the program and distribute "Participation Ideas for Cooperating Organizations," a checklist following this page.

Some advantages to having organizations cooperate are to:
- Share the responsibilities of all tasks to be done;
- Provide easier access to potential guest presenters;
- Broaden the community base from which to recruit caregiver participants;
- Broaden the community base from which to seek respite care for course participants.

Examples of organizations to involve:
- Office on Aging
- Information and Referral Service
- American Red Cross
- Health-related groups such as the American Heart Association, the American Diabetes Association, etc.
- Hospitals
- Hospices
- Home health care agencies
- Mental health organizations
- Department of Agriculture Extension Service
- Relevant university departments

Directions for using pages 15-16

PARTICIPATION IDEAS FOR COOPERATING ORGANIZATIONS

If you are planning to enlist the support of several community organizations for this program -

- Duplicate enough copies of this two-page form so each person attending the planning meeting can fill one out.

Participation Ideas for Cooperating Organizations

With the support of several organizations in the community, we can offer a valuable service to caregivers without placing a burden on any one organization and its staff.

Please indicate if you would like to participate in "Home Is Where the Care Is." Check the resources you may be able to contribute to the success of this homecare course for family caregivers.

________ I would like our organization to assist in presenting "Home Is Where the Care Is" in our community.

____
Name of organization

____
Address

____

____
Contact's name, phone number

We may be able to provide the following resources:

________ Meeting space

________ Help with publicity

______ Phone line for registration/information

________ Respite care for caregivers who would be otherwise unable to attend the class

________ Speaker(s) on the following subjects:

___ personal care
___ community resources
___ time management
___ adapting the home/safety
___ exercise
___ stress management
___ blood pressure technique
___ changing dressings

___ transfers
___ bed care
___ finances
___ legal issues
___ medications
___ nutrition
___ pulse and respiration

Speaker(s) on other topics (please specify)

____

____

________ Healthful refreshments

________ Photocopying services

________ Samples of homecare products

Thank you for attending this meeting. Please return this form before you leave and if you have indicated an interest in participating in "Home Is Where the Care Is," we will be in touch with you soon.

Program Facility

Locate facility in which to hold the program

- o Factors to consider:
    - A site that can be used for entire program;
    - A site that can loan for the program:
        - o Bed and linens
        - o Wheelchair(s)
        - o Audio-visual equipment
        - o Blood pressure equipment
    - Good access to the site by public transportation;
    - A meeting room on the ground floor or in a building with an elevator;
    - Good parking in a well-lit area.
- o Suggestions for program site:
    - Hospital
    - Nursing home
    - Recreation center
    - Senior citizens center
    - Adult day care center
- o What site gets in return:
    - Positive publicity as contributor to good of the community;
    - Chance to expose caregivers to relevant services offered at the location.

Respite Care

Make plans to assist caregiver participants who will need to arrange respite care (a substitute caregiver for the care recipient so the family caregiver can attend the program)

- o Take advantage of existing respite program(s):
    - Let existing program know at earliest date what the expected respite needs will be for the caregivers;
    - information about existing respite program(s) will also be needed for the purple AARP Community Resources booklet (example located in back of this material) if you use it in Module #2;
- o Make arrangements for respite just for program duration:
    - Organizations with potential respite volunteers:
        - o Cooperating organizations;
        - o Churches or synagogues, especially those that caregivers might belong to;
        - o High school organizations:
            - Future Homemakers of America

        - Future Nurses of America
        - Service clubs
        - Senior scout groups
    - Womens' clubs
    - Local Council of Churches
    - Hospital auxiliary
    - AARP chapter or RTA unit
- Use a bartering service in the community where caregiver might offer to do something that fits his or her homebound schedule and interests in return for respite care (mending, ironing, typing, carpentry, making phone calls, doing some baking, giving music lessons);
- If possible, make arrangements to bring ambulatory care recipients to a centralized location (even another room at the program site) where they can be cared for at the ratio of one or two/three rather than one-on-one;
- Make arrangements to add program care recipients to an existing day care program or senior citizens center and line up one more volunteer per each 2-3 care recipients for the duration of the program.

Publicity

Identify program participants

- Publicity by word-of-mouth referral
  - Caregivers suggested by:
    - Area Agency on Aging
    - Home health agencies
    - Hospital discharge planners
    - Support groups
    - American Red Cross
    - Disease-specific organizations (such as the American Cancer Society)
    - Family service agencies
    - Any other organizations participating in this program.
- Make a list of publicity targets by monthly, weekly, and daily publications or formats (See sample publicity information beginning on page 20.)
  - To reach people who can't get out, perhaps because of their caregiving situation:
    - Newsletter from Area Agency on Aging
    - Religious bulletins that are mailed to those who can't attend services
    - Newspapers
    - Radio (brief talk show format preferable to public service announcement, or "PSA")
    - Health department publicity
    - Social services publicity
    - Information and Referral service
    - Department of Agriculture Extension Service publicity
    - Community college or open university program offerings.
  - For people who are able to be out:
    - Senior citizen centers
    - Religious bulletins
    - Hospital bulletin boards.

Information or registration phone number

- If an information or registration phone number is given out, make certain that anyone who might answer that phone knows of, if not about, the program and can at least refer the caller to the proper person; you may want to type up brief information cards to place at each phone where calls may come in.

Directions for using page 21

SAMPLE PROMOTIONAL FLYER

If you have a way to duplicate and distribute flyers to publicize this program, the following sample may help you. To use this sample as it is:

- In the area designated "SPACE FOR ART" you can scotch tape on some caring related art work, the logos of the cooperating organizations if they will fit, or some other item that will add an eye-catching presence to the flyer.
- Neatly hand-letter the location of the course, the dates of the course, and the participating organizations in the spaces provided.
- If respite care will not be provided for the caregivers who need it to attend the course, delete that sentence ("Care can be arranged...") by taping a piece of white paper over it before reproducing.
- If a phone information and registration line is being used, neatly hand letter the phone number in the space provided. MAKE SURE ANYONE WHO MIGHT ANSWER THAT PHONE LINE AT LEAST KNOWS OF THE PROGRAM AND KNOWS WHO MIGHT BE ABLE TO ANSWER QUESTIONS ABOUT IT.
- Before reproducing, tape a strip of paper over the 3 holes punched in the left margin.
- Reproduce on colored or white paper.

If you cannot use this sample by simply filling in information, or blocking out things that do not apply to your program, then create your own flyer by typing or putting art work on plain white paper. Use this sample as a reminder of the kind of information your flyer should include.

Are You, or Someone You Know, caring at home for an ill family member or friend?

Learn about our program

Home Is Where the Care Is

"Home is Where the Care Is" is a course to help family caregivers, or people who are caring in the home for someone who is ill, handicapped, or older. Over the course of eight sessions we will introduce the caregiver to resources available in the community, share tips and skills to make giving personal care to the friend or family member easier, talk about exercise, nutrition and medications, go over some important financial and legal information, and much more.

SPACE
FOR
ART

Location:

Dates:

Co-sponsored by:

Care can be arranged for your friend or family member while you attend Home Is Where the Care Is.

Call now for more information:

Directions for using page 23

SAMPLE PRESS RELEASE

The following page is a sample of a press release. IT WILL NEED TO BE RETYPED WITH THE APPROPRIATE INFORMATION FILLED IN BEFORE IT CAN BE USED.

- Each place in the copy of the sample where there are parentheses indicates where specific information about your program needs to be inserted.
- Retype the press release including your program information, double spacing the lines, and duplicate it for distribution.
- Do not use the heading "SAMPLE" on the actual press release.

SAMPLE

PRESS RELEASE

For Immediate Release

Information contact:
(name)
(phone number)

(NAMES OF PARTICIPATING ORGANIZATIONS) WILL HOLD (FREE) COURSE ON CARING IN THE HOME FOR AN ILL OR ELDERLY FAMILY MEMBER OR FRIEND

(Names of participating organizations) will hold a (free) course on caring in the home for an ill or elderly loved one, each (Day of the week) and (Day of the week) during (Month), from (starting time of program) to (time the program ends) at (Location). For more information or to register, contact (Name) at (phone number).

Entitled "Home Is Where the Care Is," the course has been prepared by the American Association of Retired Persons to meet the needs of the increasing number of persons who take care of ill or elderly loved ones in their homes. Caregivers nationwide were interviewed to discover their problems and most important needs, and the course is a direct result of these interviews. Instruction and tips will show caregivers how to provide personal care for their loved ones, how to identify and use community resources, how to have more free time, what special safety precautions may be needed in the home, how to exercise the physically restricted person, how to provide bed care, and how to solve financial and legal problems, Other topics include medications, nutrition, and family relationships.

Caregivers will learn many useful tips, such as how to wash the hair of someone lying in bed, what respite care is and where to find it, why a bedspread can be dangerous, what to do if the care recipient falls, what financial resources may have been overlooked, how to pack extra nutrition into a skimpy diet, and how to rate a facility that might help the caregiver provide care. Caregivers will also be able to ask questions about their specific homecare situations.

Directions for using

SAMPLE PUBLIC SERVICE ANNOUNCEMENTS (PSAs)

Public Service Announcements are aired free of charge on radio and TV stations for non-profit organizations. Call the Community Relations Director of your local station(s) to learn the requirements and deadlines for submitting a PSA. A radio station will usually ask to have the copy 2 weeks before it is to be run and a TV station 4 weeks in order to schedule studio time for taping.

If you have a chance to run the PSA on television, suggest in a cover letter to the Community Relations Director some caregiving-type activity that can be shown while the copy is being read. Watching an activity is more eye-catching than watching someone just sitting in front of the camera reading. The station may or may not be able to use your idea.

The parentheses in the PSA copy indicate where specific information about your program needs to be filled in before the copy is typed double-spaced and sent to the station(s). After you have filled in your specific information, read the PSA out loud to see if it fits in the 20, 30 or 60 second time slot. It should be one second under the limit. The person directing the actual taping of the PSA will do minor editing to make sure it is the correct length if necessary.

SAMPLE PUBLIC SERVICE ANNOUNCEMENTS (PSAs)

20 SECOND PSA

If you provide care in your home for someone who is ill or elderly, or if you know someone who does, you should know about a course designed especially for the family caregiver. It's being offered by (Name of organization) and (Name of organization). For more information call (phone number). That's (repeat the phone number).

30 SECOND PSA

Are you providing care at home for someone who is ill or elderly? Do you know someone who does? (Name of organization) and (Name of organization) want you to know about their course that could make a family caregiver's job easier. Sessions will be held eight (afternoons, evenings) during (Month). Learn about dressing and bathing your loved one, safety precautions, nutrition, how to manage financial and legal affairs, and much more. For information call (phone number). That's (repeat the phone number).

60 SECOND PSA

If you are providing care at home for someone who is ill or elderly, we would like to ask you a few questions.

- Do you know how to wash the hair of someone lying in bed?
- Do you know how a bedspread can be dangerous?
- Do you know what to do if your loved one falls?
- Are you receiving all the financial benefits you deserve?
- Do you know how to pack extra protein into a skimpy diet?

If you answered "no" to any of these questions, this information is for you. On (Day of the week) and (Day of the week) (afternoons, evenings) during the month of (Name of month), (Name of organization) and (Name of organization) are presenting a (free) program for family caregivers at (Location). Answers to these questions and others will be covered, including dressing and bathing, safety precautions, nutrition, how to manage financial and legal affairs, medications, and more. For information or to register, please call (phone number). That number again is (repeat phone number).

Choosing a Guest Presenter

Each module planning sheet has suggestions about community resource persons to demonstrate skills or speak to the caregivers. Professionals from the community should be invited for topics that you, as host, do not feel comfortable delivering, for whatever reason. Guest presenters will also add variety to the program.

SELECTION PROCESS:

Decide which topics require a guest presenter.

Call the suggested resource or one of your own choosing.

Ask if there is someone in the organization who can speak to the specific topics of the outline and explain the main points to be covered.

Once a speaker has been identified, using copies of items in "VI-Information for Guest Presenter," mail him or her:

- Confirmation Letter to Guest Presenter;
- Joint Responsibilities of Guest Presenter and Host;
- Tips for Group Facilitation;
- Discussing Emotions with Caregivers;
- Overview of "Home Is Where the Care Is" for Guest Presenter;
- The relevant outline for presentation, both detailed and summary versions;
- A sample of any handouts being planned for the module.

After the guest presenter has had time to receive the written information, call to ask if there are any questions and to clarify his or her role; indicate that information about the caregivers in the class will arrive shortly before the date of his or her presentation.

Mail "Profile of Caregivers," a form also found in section VI, to the guest presenter one week before the presentation, both for information and to serve as a reminder of the date.

Suggestions for Refreshments

It is hoped that this program will become a special mental health break for the caregivers in which they feel pampered for a change rather than being the ones doing the pampering.

Toward this end, in each module it is suggested that you plan a small and light refreshment. If a module falls near a holiday consider a few special decorations. Fresh flowers are a treat on any day. Caregivers should never be asked to contribute to this as it might produce rather than relieve stress for them.

Since this program is on dealing with illness, any food served should be healthful. Rather than this being an out-of-pocket expense, consider getting a contribution from a grocery store in return for your publicizing that the store has made the donation for the good of this community project, or for listing the store as a contributing organization. A $60 donation would probably supply snacks for all the modules. If the store has any special services that could be mentioned when you cover "Community Resources," (such as home delivery of groceries) be sure you both list the service(s) and tell the manager they will be listed when you ask for the donation.

Another possibility for the refreshments is for the cooperating organizations to take turns providing them.

Ideas for food and drinks to serve alone or in combination are:

- chunks of fruit
- vanilla yogurt
- unsalted nuts
- unsweetened fruit juice
- cheese cubes
- ice water with optional lemon slices
- unsalted popcorn (to go with the film perhaps)
- unsalted nut/seed/fruit mix
- vegetable sticks with a dip of seasoned low fat cottage cheese
- unsalted, or low salt, snack crackers

Try to avoid serving coffee, tea, sodas, doughnuts, cookies and other sweets.

Tips for Group Facilitation

Knowing something about group process could be a key to making "Home Is Where the Care Is" very successful. Every caregiver needs to feel important and be a part of the group during each module; every caregiver needs to feel that what he or she has to say is very important. To accomplish this the host and guest presenter should concentrate on the following.

PRACTICE GOOD LISTENING SKILLS

- Don't try to do anything else while a caregiver is talking; give undivided attention.
- If you think of something important to say while listening, jot down a key word as a reminder so you can share the thought later without interrupting the caregiver.
- If you don't understand or notice that someone else doesn't understand what a caregiver has said, ask for clarification; someone else may be unclear but not want to admit it.

ENCOURAGE OPEN DISCUSSION

- No concern voiced by a caregiver is unimportant; make sure a supportive, not judgmental, response is the last thing said to the caregiver so that person will continue to feel comfortable sharing.
- On a given topic, ask caregivers for examples or ideas based on their own experience.
- Encourage a caregiver to share a thought completely with a brief comment ("Uh-huh", "I see") or nod of the head without interrupting the caregiver's train of thought.
- If sharing on a subject would be valuable to the group but difficult due to the caregiver having to make himself or herself vulnerable, ask that each person share but that no one respond; host can let caregivers feel they have been heard with a supportive comment which neither judges nor belittles anything that has been said.
- Make sure that each caregiver gets help with specific problems to encourage that caregiver to jump into the conversation more often.

PREVENT ONE CAREGIVER FROM MONOPOLIZING THE DISCUSSION

- To politely cut off a caregiver who is straying from the subject try, "It seems you have a variety of concerns; let's talk about ______________________ a bit later."
- When it is time to get feedback from the caregivers, don't ask the most talkative one to respond first.
- Politely interrupt the talkative caregiver to ask another caregiver if she or he has had a similar experience.

Discussing Emotions with Caregivers

Caregivers and care recipients are known to experience a myriad of emotions - both positive and negative. "Home Is Where the Care Is" could be especially helpful in dealing with many of the negative emotions if the caregivers are given a chance, and are encouraged, to express both what they are feeling and what they think the care recipient might be feeling. It takes keen listening on the part of the host and guest presenter to pick up on hints of those emotions when caregivers aren't speaking about them openly.

Emotions caregivers and care recipients might experience relative to a given subject are listed at the beginning of each module outline for the guest presenter, and on the module planning sheet for the host. In addition, a more detailed explanation of what the caregiver, or care recipient, might be feeling is inserted in the guest presenter's outline. Please use these as discussion aids with the caregivers. In many cases, dealing with the emotions is as important as dealing with the subject matter itself.

The eighth module is mainly on the topic of emotions. Make a note on your #8 module planning sheet about emotions from earlier modules that you want to come back to, either because they were skipped entirely, or because there would be value in discussing them more fully.

If the guest presenter is not picking up on the emotions being expressed or hinted at by the caregivers, the host should pick up on that part of the module presentation.

Directions for using page 31

THE MOST IMPORTANT THING

"The Most Important Thing" is a brief evaluation form for the caregiver to fill out it in the last couple minutes of each module. It is designed to provide a focus for the caregiver on the module's subject matter, and feedback to the host while thoughts are still fresh in the caregiver's mind.

Duplicate enough copies of this form to distribute to each caregiver at the end of each module.

The Most Important Thing

At the end of each session we will distribute this sheet of paper. Please take just a minute to fill it out, being as specific as possible. Your comments will be helpful to us.

THE MOST IMPORTANT THING I LEARNED TODAY is (An example might be, "I had never heard of toilet seat extensions until today and it is something we can definitely use at home."):

What I especially enjoyed about today is:

One thing I didn't like about today is:

Thank you very much for filling out this form. See you next time!

Directions for using pages 33-34

CAREGIVER'S EVALUATION OF "HOME IS WHERE THE CARE IS"

Duplicate enough copies of this questionnaire to distribute to each caregiver after the eighth module. If the ninth optional module is on a subject, or subjects, where the whole group is still together in one meeting place the evaluation could be distributed after the ninth module.

Please send copies of these completed evaluations back to AARP along with your evaluation of this course. AARP is always interested in making educational materials as relevant as possible and the evaluations of this course from both the caregivers and the host will assist in that process.

The address for mailing the evaluations is:

AARP - HAS
1909 K Street, N.W.
Washington, D.C. 20049

Caregiver's Evaluation of "Home Is Where The Care Is"

Was attending this course worthwhile for you? Yes___ No___

Would you recommend it to other caregivers? Yes___ No___

What did you like best about the course? ______________________

____

____

What suggestion(s) would you make to improve it? ________________

____

____

Have you made any changes at home, in the way you perform certain tasks, or in the way you relate to your loved one as a result of things you learned in this course?

Yes___ No ___

If you answered "yes," please say what is different now?

____

____

____

Have you sent for any of the resources that were mentioned in the course?

Yes ____ No ____

If you answered "yes," which resources?

____

____

Have you contacted any organization(s) in your community for assistance as a result of this course?

Yes ___ No ___

If you answered "yes," which one(s)?

____

____

Did you find the people you dealt with helpful? Yes___ No___

Do you have a better feel for how to get help with caregiving responsibilities now that you have taken this course? Yes___ No__

Did you pay to take this course? Yes ___ No ___

If you answered "no," would you have paid to take this course?

Yes ___ No ___

Thank you very much for taking the time to complete this evaluation.

Directions for using page 36

HOST'S EVALUATION TO RETURN TO AARP

AARP is very interested in your reaction to this program material and, if you used it, how successful you felt your course was.

After your program is over, or after you have perused the program material if you decide not to use it, please fill in this evaluation completely and mail it to:

AARP-HAS
1909 K Street, N.W.
Washington, DC 20049

If you used the material, we would also appreciate copies of the evaluations from the caregivers.

Thank you for your feedback!

Note: If you plan to offer this course to the community more than once, photocopy this evaluation form rather than sending us the original.

Host's Evaluation

How did you find out about this program material? ______________

____

Did you find the steps to planning and organizing this program easy to follow?

Yes ___ No ___

What would have made the steps easier to follow? ______________

____

____

Was your "Home Is Where the Care Is" program a success?

Yes ___ No ___ How many caregivers attended? __________

Did you distribute AARP's purple Community Resources booklet?

Yes ___ No ___ If "yes," was it helpful? Yes ___ No ___

Did you distribute AARP's turquoise Additional Resources booklet?

Yes ___ No ___ If "yes," was it helpful? Yes ___ No ___

Did you find the materials for preparing the guest presenters helpful?

Yes ___ No ___

Do you plan to host another "Home Is Where the Care Is" program?

Yes ___ No ___ Possibly ___

We appreciate your time to fill out and return this form. Please include comments about why you did not plan a program if that was the case. Any other comments you have will be welcomed.

____

____

Directions for using "IV Outlines for Host"

In this section you will find for each module:

"Host's Preparation and Checklist" to get ready for the module
- Suggestions for guest presenters
- Checklist of the items to send the guest presenter
- Other preparation

"Host's Presentation Outline" to use on the day of the module
- The goals of the module
- The emotions you might hear from the caregivers
- The time allowed for each portion of the module
- Discussion suggestions for each portion of the module for which the host is responsible (in most cases that is the opening and closing)

Note: These two guides for the host are a little more involved for the first two modules because of the few extra tasks to be done to get the course started.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #1
ON
INTRODUCTION AND PERSONAL CARE

PREPARE CAREGIVERS

Using the materials in "V - Information for Caregiver," mail out to each of the caregivers as they sign up for the program:

- Logistics for Program
- Caregiver Questionnaire
- Overview of Program for Caregiver
- Information for Short-Term Respite Caregiver (if appropriate)
- Addressed, stamped envelope in which the Questionnaire and Overview forms will be returned before Module #1 begins; any fee being charged for the program can be returned also.

CHECKLIST

Fill in last name of each caregiver; record date the information is mailed out and date it is returned for each one.

	Sent	Returned		Sent	Returned

PREPARE GUEST PRESENTER

Read over "Choosing a Guest Presenter," page 26.

Seek guest presenter on personal care from:
- Visiting Nurses Association
- Home health agency or
- Hospital.

Using materials in "Section VI-Information for Guest Presenter," mail out: Check when mailed

- Confirmation Letter to Guest Presenter ____
- Joint Responsibilities of Guest Presenter and Host ____
- Tips for Group Facilitation ____
- Discussing Emotions with Caregivers ____
- Overview of "Home Is Where the Care Is" for Guest Presenter ____
- Module #1 Detailed Outline ____
- Module #1 Summary Outline ____
- Handouts you plan to use:

  ________________________________ ____

  ________________________________ ____

  ________________________________ ____

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

- Profile of Caregivers ____

OTHER PREPARATION

Check when done

- Confirm meeting room logistics
  - time you will be using the facility ____
  - number of chairs you need ____
  - number of tables ____
- Plan a light, healthy refreshment ____
- Prepare/collect examples of some personal care aids that go with outline of Module #1:
  - borrow from hospital, nursing home, medical supply company ____

Check when done

o Duplicate or order for each caregiver any handouts you plan to use (you may want to order AARP's turquoise Additional Resources booklet, an example of which is included in VII-Optional Booklets):

______________________________ ____

______________________________ ____

______________________________ ____

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HOST'S PRESENTATION OUTLINE FOR MODULE #1
ON
INTRODUCTION AND PERSONAL CARE

The GOALS of Module #1 are to:

- Begin helping caregivers get acquainted with each other and have caregivers share a little about themselves;
- Impress upon caregivers the importance of helping their care recipients remain as independent as possible;
- Provide tips to make personal care easier;
- Deal with the emotional aspects of personal care.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Caregiver feeling
  - unloved or unappreciated for all the work being done;
  - guilty over stretching the truth to accomplish a goal;
  - like a failure for inability to cope;
  - pride over helping care recipient be independent;
- Caregiver and care recipient feeling embarrassed or ashamed about toilet issues;
- Care recipient feeling
  - sense of loss in new situation;
  - depressed over self-image.

GETTING ACQUAINTED WITH EACH OTHER (35 minutes)

(While caregivers are arriving, distribute "Caregiver Questionnaire" and "Overview" to any who did not receive them in the mail.)

Introduction and Welcome (5 minutes)

- Welcome
- Overview of the program topics
- Logistical information

Introduction to Each Other (30 minutes)

- If up to 12 caregivers in the group:
  - Pair caregivers (2 minutes)
    - Host or guest presenter should be part of a pair if number of caregivers is uneven
  - Ask couples to share with each other (5 minutes)
    - First names
    - How long each has been a caregiver
    - Diagnosis of care recipient
    - How each found out about this program
  - Each person introduces partner to group (23 minutes)
    - Example: "This is Mary; she has been caring for her husband who is diabetic for 4 months; she found out about this program through her church."
  - ADVANTAGES of this method of introduction

    - Each caregiver knows someone in the group right from the beginning
    - Because they are being introduced by someone else, no caregiver can monopolize the time by going into great detail about his or her personal situation
- If 13-20 caregivers in the group (30 minutes)
  - Ask each caregiver to share with the group:
    - First name
    - How long each has been a caregiver
    - Diagnosis of care recipient
    - How each found out about this program
  - Be prepared to limit talkative caregivers

- Sum up with a comment on the variety of problems being dealt with.

- Introduce the guest presenter.

GUEST PRESENTATION ON PERSONAL CARE (70 minutes not counting break)

Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 102 through 118.

REFRESHMENTS - Take 10-minute refreshment break after "dental care"

WRAP-UP AND SHARING (5 minutes)

Collect "Caregiver Questionnaire" and "Overview" forms

Hand out AARP's turquoise Additional Resources booklet if you are using it; review the resources on pages 2 through 4; encourage caregivers to bring this booklet with them each week.

Distribute "The Most Important Thing" and collect it.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #2
ON
COMMUNITY RESOURCES AND TIME MANAGEMENT

PREPARE GUEST PRESENTER

Seek guest presenter on community resources (host may simply want to cover "Time Management" since it is not technical information) from:

- o Area Agency on Aging (AAA)
- o Information and Referral or
- o Hospital discharge planner.

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

- o Confirmation Letter to Guest Presenter ____
- o Joint Responsibilities of Guest Presenter and Host ____
- o Tips for Group Facilitation ____
- o Discussing Emotions with Caregivers ____
- o Overview of "Home Is Where the Care Is" for Guest Presenter ____
- o Module #2 Detailed Outline-Community Resources ____
- o Module #2 Summary Outline-Community Resources ____
- o Module #2 Detailed Outline-Time Management (unless host plans to cover this topic) ____
- o Module #2 Summary Outline-Time Management ____
- o Handouts you plan to use

  Community Resources booklet (AARP's from VII-Optional Booklets, or your local version) ____

  ____ ____

  ____ ____

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

- o Profile of Caregivers ____

OTHER PREPARATION

Check when done

- o Confirm meeting room logistics
  - time you will be using the facility ____
  - number of chairs you need ____
  - number of tables ____
- o Plan a light, healthy refreshment ____

OTHER PREPARATION (continued) Check when done

- Pens or pencils so caregivers can fill in Community Resources booklets, if necessary. ______
- Duplicate, prepare, or order for each caregiver, the guest presenter, and yourself a community resources booklet. If your Agency on Aging does not have one, or know of a local organization that does, you may want to order AARP's purple Community Resources booklet included in VII- Optional Booklets. ______
  - If necessary, prepare additional sheet of special local resources for caregivers which may not be included in the booklet you choose to use. ______
  - If you are using AARP's purple booklet, agree between yourself and the guest presenter who will write in the local information to be shared with the caregivers during Module #2. ______
  - Review the "Caregiver Questionnaire" copies returned from caregivers:
    - Mark on host's and guest presenter's copies of "Community Resources" specific resources you want to mention for a particular caregiver. ______
- Review comments about specific needs on the caregivers' "Overview..." forms which will not be covered by the regular course material; begin plans for the ninth module:
  - Invite guest presenter(s) to speak to whole group
  - Have guest presenter(s) speak to sub-divided group
  - Have caregivers' specific needs met by arranging meetings out in the community with appropriate organizations. ______

HOST'S PRESENTATION OUTLINE FOR MODULE #2
ON
COMMUNITY RESOURCES AND TIME MANAGEMENT

The GOALS of Module #2 are to:

- Discuss community and other resources that caregivers might begin using immediately;
- Have caregivers share experiences with resources they have already tried;
- Help caregivers feel comfortable seeking and accepting assistance;
- Look at time management in terms of the relationship between caregiver and care recipient in addition to using time most effectively.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Caregiver feeling
  - overwhelmed by job to be done;
  - uncomfortable using community resources;
  - resentful of time caregiving takes;
  - burned out;
- Care recipient feeling
  - isolated;
  - self-pity;
  - dissatisfied with living situation.

WELCOME - TIME FOR GROUP SHARING (15 minutes)

Use the sharing time, either informally or as a group, to ask each caregiver how she or he is. Too often friends and family will ask about the care recipient but not about the caregiver. The caregiver needs to be remembered, cared about, and given positive strokes for the tough job each is doing. If you are aware that any caregiver meant to try some new idea or technique learned in Module #1, be sure to ask the outcome of that venture.

At this time, distribute Community Resources booklet and writing utensils. Then introduce guest presenter.

GETTING ACQUAINTED WITH COMMUNITY RESOURCES (65 minutes)

- After 40 minutes take a 10 minute refreshment break

Outline for guest presenter is located in "VI - Information for Guest Presenter" of this program material, pages 119 through 123.

TIME MANAGEMENT (20 minutes)

Outline for guest presenter or host is located in "VI-Information for Guest Presenter" of this program material, pages 124 through 126.

WRAP-UP AND SHARING (10 minutes)

Ask caregivers to bring Community Resources booklet back with them each time to make notes when other resources are mentioned.

Review pages 6 through 8 of AARP's turquoise Additional Resources booklet.

Ask caregivers to wear comfortable, stretchy clothing next time in order to learn some easy exercises.

Distribute handout "The Most Important Thing" and collect it.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #3 ON HOME ENVIRONMENT AND EXERCISE

PREPARE GUEST PRESENTER(S)

Seek guest presenter on home environment from:
- Cooperative Extension Service (for home adaptation focus)
- Fire Department (for home safety focus).

Seek guest presenter on exercise from:
- Physical therapy department of local hospital or university (for focus on care recipients' exercises) or
- Yoga instructor (for focus on relaxation techniques for caregiver).

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

- Confirmation Letter to Guest Presenter ______
- Joint Responsibilities of Guest Presenter and Host ______
- Tips for Group Facilitation ______
- Discussing Emotions with Caregivers ______
- Overview of "Home Is Where the Care Is" for Guest Presenter ______
- Module #3 Detailed Outline-Environment ______
- Module #3 Summary Outline-Environment ______
- Module #3 Detailed Outline-Exercise ______
- Module #3 Summary Outline-Exercise ______
- Handouts you plan to use

  ________________________________ ______

  ________________________________ ______

  ________________________________ ______

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter(s):

- Profile of Caregivers ______

OTHER PREPARATION

Check when done

- Confirm meeting room logistics
  - time you will be using the facility ______
  - number of chairs you need ______
  - number of tables ______
  - 16 mm film projector and screen ______
    - extension cord and 3-pronged adaptor ______
    - person to operate projector
      - check with local high school

or junior college to get a volunteer if necessary

- Plan a light, healthy refreshment

- Suggested resources for Module #3:
  - 18 minute film, The Hundred Penny Box. Rental cost is $40 for 3 days. Order 4 to 6 weeks in advance from:

    Audience Planners
    5107 Douglas Fir
    Calabassas, CA 91302
    818-884-3100
    800-624-8613

    - state due date of 1-2 days before needed
    - film synopsis - Mike's mother wants to throw out the half-rotten wooden box in which Aunt Dew keeps pennies for each year of her life. But Aunt Dew protests, "When I lose my hundred penny box, I lose me," and Mike movingly defends her. The loss of independence, the struggle to maintain identity and orientation, the life review process, and the unrecognized strengths of the frail elderly are clearly illustrated. Also shown are difficulties in the caregiver's role and the caregiver's conflicting feelings about these responsibilities. Michael's interactions with Aunt Dew suggest sensitive ways of relating to the elderly.

  - "Home Safety Checklist for Older Consumers"
    - free
    - order one copy for each caregiver 6 to 8 weeks in advance from:

      US Consumer Product Safety
      Commission
      Washington, DC 20207

HOST'S PRESENTATION OUTLINE FOR MODULE #3
ON
HOME ENVIRONMENT AND EXERCISE

The GOALS of Module #3 are to:

- Provide practical tips on setting up care recipients' home and room for both safety and ease of care;
- Deal with emotional aspects of making changes in the home;
- Stress the importance of exercise for both caregiver and care recipient;
- Provide examples of exercises.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Care recipient feeling
  - insecure, frustrated or homesick in the different surroundings;
  - frustrated that she or he can't participate in household chores;
  - resentful of caregiver's good health;
  - unloved or not needed because someone else is doing his or her job;
  - anxious because some jobs around the house aren't getting done;
  - hurt, resentful, fearful when the caregiver goes out;
- Caregiver feeling
  - angry that home is no longer as clean;
  - insecure, not wanting to let go of the past;
  - guilty about having fun.

SHARING AND REFRESHMENTS (7 minutes)
Ask caregivers to share experiences of using community resources.

SHOW FILM and brief discussion (23 minutes)

GUEST PRESENTATION ON HOME ENVIRONMENT (40 minutes)
Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 127 through 135.

GUEST PRESENTATION ON EXERCISE (45 minutes)
The first 5-10 minutes of exercise presentation functions as a break from sitting by doing some stretches.

Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 136 through 140.

WRAP-UP AND SHARING (5 minutes)

Review pages 8 through 20 of AARP's turquoise Additional Resources booklet, if it is being used.

Distribute "The Most Important Thing" and collect it.

Confirm your plans with caregivers for the ninth module
o What small group(s) will be set up for special training
o Opportunity for caregivers to make final input to the plans

HOST'S PREPARATION AND CHECKLIST FOR MODULE #4
ON
MOBILITY AND BED CARE

PREPARE GUEST PRESENTER

Seek guest presenter on mobility from:
o Physical therapy department of university or hospital or
o Emergency rescue squad.

Seek guest presenter on bed care from:
o Visiting Nurses Association or
o Nursing home.

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

o Confirmation Letter to Guest Presenter _____
o Joint Responsibilities of Guest Presenter and Host _____
o Tips for Group Facilitation _____
o Discussing Emotions with Caregivers _____
o Overview of "Home Is Where the Care Is" for Guest Presenter _____
o Module #4 Detailed Outline-Mobility _____
o Module #4 Summary Outline-Mobility _____
o Module #4 Detailed Outline-Bed Care _____
o Module #4 Summary Outline-Bed Care _____
o Handouts you plan to use

____ _____

____ _____

____ _____

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

o Profile of Caregivers _____

OTHER PREPARATION

Check when done

o Confirm meeting room logistics
  - time you will be using the facility _____
  - number of chairs you need _____
  - number of tables _____
  - secure use of a bed, linens, wheelchair, transfer board
    o if a bed is not available, use an exercise mat or a padded 6' table

o Plan a light, healthy refreshment _____

HOST'S PRESENTATION OUTLINE FOR MODULE #4
ON
MOBILITY AND BED CARE

The GOALS of Module #4 are to:

- Make mobility for the caregiver and care recipient safer and easier;
- Stress the need for the caregiver to take care of himself or herself both physically and emotionally.

EMOTIONS to listen for during conversation, reiterate for emphasis,or mention if no one does:

- Caregiver feeling
  - angry about the illness;
  - frustrated about being tied down;
  - a need to practice denial;
  - too proud to seek help;
- Care recipient feeling
  - angry about dependency;
  - afraid to try something new;
  - insecure about home care.

WELCOME AND SHARING (10 minutes)
Ask if anyone decided to make any changes in his or her home based on information shared in module #3.

GUEST PRESENTATION ON MOBILITY (45 minutes)

Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 141 through 150.

REFRESHMENT BREAK (10 minutes)

GUEST PRESENTATION ON BED CARE (45 minutes)

Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 151 through 155.

WRAP-UP AND SHARING (10 minutes)

Review pages 5 and 21 of AARP's turquoise Additional Resources booklet if you are using it.

Distribute "The Most Important Thing" and collect it.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #5
ON
FINANCES

PREPARE GUEST PRESENTER

Seek guest presenter on finances from:

- AARP Medicare/Medicaid Assistance Program (MMAP) volunteer (focus on Medicare and Medicaid benefits and regulations)
  - Contact your AARP Area Office or the national office for assistance in scheduling a MMAP volunteer
- Social Security Administration office (focus on Federal financial resources) or
- Agricultural Department Extension Service agent (focus on financial management).

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

- Confirmation Letter to Guest Presenter ______
- Joint Responsibilities of Guest Presenter and Host ______
- Tips for Group Facilitation ______
- Discussing Emotions with Caregivers ______
- Overview of "Home Is Where the Care Is" for Guest Presenter ______
- Module #5 - Detailed Outline ______
- Module #5 - Summary Outline ______
- Handouts you plan to use

  Copies of pages 22-25 of AARP's turquoise Additional Resources booklet on check handling, if desired ______

  ____ ______

  ____ ______

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

- Profile of Caregivers ______

OTHER PREPARATION

Check when done

- Confirm meeting room logistics
  - time you will be using the facility ______
  - number of chairs you need ______
  - number of tables ______
- Plan a light, healthy refreshment ______

o Suggested resources
  - "Your Medicare Handbook" is available free from your local Social Security Office (Allow 9 weeks)
  - "Information on Medicare and Health Insurance for Older People" is available free from:

    AARP Fulfillment (stock #C38)
    1909 K Street, NW
    Washington, DC 20049

    (Allow 6 weeks)
  - If "Your Medicare Handbook" is not available from the Social Security Office, photocopy pages 56 through 59 of this material to use with AARP's "Information...for Older People" booklet

Directions for using pages 56-59

What Medicare Covers

and

What Medicare Does Not Cover

- If you cannot get copies of "Your Medicare Handbook" from your Social Security Office, duplicate the following four pages (What Medicare Covers - 2 pages, and What Medicare Does Not Cover - 2 pages) which are adapted from the Social Security Office booklet
- Cover the 3 holes punched in the side with a strip of paper before duplication.
- Use these handouts with AARP's booklet "Information on Medicare and Health Insurance for Older People," stock #C38. Ordering information is on page 54.

In addition to what is listed in the AARP booklet:

WHAT MEDICARE COVERS

DENTAL CARE

Surgery of the jaw or related structures, setting fractures of the jaw or facial bones, or services that would be covered when provided by a doctor.

If you must be hospitalized for dental work that is not covered, the hospital stay will be covered.

VISION CARE

Medicare-approved corrective lenses following a cataract operation, artificial eyes, and examination services related to aphakia (absence of the natural lens of the eye).

FOOT CARE

Removal of plantar warts, treatment of mycotic toenails once every 60 days unless doctor certifies more frequent treatment is needed, routine foot care if a medical condition, such as diabetes, affects the lower limbs.

FOREIGN HEALTH CARE

If you are in the U.S. when an emergency occurs, and a Canadian or Mexican hospital is closer than the nearest U.S. hospital which can provide the services you need; or, if you live in the U.S. and a Canadian or Mexican hospital is closer than the nearest U.S. hospital which can provide the services you need whether or not it is an emergency; or, if you are in Canada on the most direct route between Alaska and another state and an emergency requires you be in a Canadian hospital, Medicare will cover the costs.

CARE IN A PSYCHIATRIC HOSPITAL

In a lifetime Medicare will pay for 190 days of care.

SECOND OPINION BEFORE SURGERY

Medicare will pay for the second opinion in the same way it pays for other services by doctors.

OUTPATIENT TREATMENT OF MENTAL ILLNESS

A maximum payment of $250 is payable in one year.

OUTPATIENT HOSPITAL SERVICES

The same things are covered that would be covered if patient were in the hospital.

AMBULANCE TRANSPORTATION

If the service is Medicare approved and transportation by another means would endanger the patient's health.

PROSTHETIC DEVICES

If needed to substitute or support an internal body organ, and artificial limbs

DURABLE MEDICAL EQUIPMENT

To rent or buy, depending on which is most economical, equipment prescribed by a doctor that

- serves mainly a medical purpose
- can be used repeatedly
- will generally not be useful to someone who does not have an illness or injury.

In requesting reimbursement for Durable Medical Equipment, be prepared to tell the Medicare carrier reviewing the request how long the equipment will be needed and what the expected cost differences are between renting the equipment for the expected period of time, or buying the equipment.

PORTABLE DIAGNOSTIC X-RAY SERVICES

If ordered by the doctor and provided by a Medicare-certified supplier.

NURSING HOME CARE

Limited coverage for care in a skilled nursing facility if ALL five of the following conditions are met:

- you have been in a hospital at least 3 days in a row before transfer to the skilled nursing facility
- you are transferred to the facility because you require care for a condition which was treated in the hospital
- you are admitted to the facility within 30 days after you leave the hospital
- a doctor certifies that you need, and you do receive, skilled nursing or rehabilitation services daily
- a Peer Review Organization or Utilization Review Committee does not disapprove your stay

(NOTE: Most nursing homes in the U.S. are NOT considered skilled nursing facilities and many skilled nursing facilities are not certified by Medicare. If you are unsure about a facility, ask the home or call the Social Security office.)

In addition to what is listed in the AARP booklet:

WHAT MEDICARE DOES NOT COVER

ACUPUNCTURE

CARE DEEMED NOT "REASONABLE AND NECESSARY" for the diagnosis or treatment of an illness or injury

If care recipient is in a hospital or skilled nursing facility getting care that could be provided elsewhere, the stay would not be considered "reasonable and necessary"

If care recipient stays in a hospital or skilled nursing facility longer than necessary, Medicare payments would end when further inpatient care is no longer "reasonable and necessary"

If a doctor treats care recipient for a medical problem more frequently than is usual in your geographic area, Medicare will not pay for the extra visits

CHIROPRACTIC SERVICES

Any diagnostic or therapeutic services, including X-rays (other than manual manipulation of the spine to correct a subluxation that can be demonstrated by X-ray, which is covered)

CUSTODIAL CARE

That is, care which is primarily for the purpose of meeting personal needs and could be provided by persons without professional skills or training: walking, getting in and out of bed, bathing, dressing, eating, taking medicine. Medicare will not pay for custodial care even if it is being provided for by an approved service provider.

DENTAL CARE

Care in connection with the treatment, filling, removal, or replacement of teeth; root canal therapy; surgery for impacted teeth; dental plates and other surgical procedures involving the teeth or structures directly supporting the teeth.

EYEGLASSES AND EYE EXAMINATIONS

Prescribing, fitting, or changing eyeglasses (other than Medicare-approved corrective lenses needed after a cataract operation, which are covered).

FOOT CARE

Routine care (other than care for a medical condition that affects the lower limbs, which is covered) such as hygienic care, treatment of flat feet or other structural misalignments of the feet, removal of corns, calluses and most warts.

FOREIGN HEALTH CARE

Care other than in the 50 U.S. states and the District of Columbia, Puerto Rico, the Virgin Islands, Guam, American Samoa and the Northern Mariana Islands is considered "foreign." A few exceptions apply to Canada and Mexico (see What Medicare Covers).

HEARING AIDS AND HEARING EXAMINATIONS

Prescribing, fitting, or changing hearing aids.

HOMEMAKER SERVICES

Other than those provided by hospice, which are covered.

INJECTIONS

Those which can be self-administered, such as insulin.

NATUROPATHS' SERVICES

NURSING HOME CARE

Unless it is in a skilled nursing facility and meets other specified criteria (see What Medicare Covers).

ORTHOPEDIC SHOES

Unless they are part of a leg brace and are included in the orthopedist's charge.

SERVICES PERFORMED BY IMMEDIATE RELATIVES OR MEMBERS OF YOUR HOUSEHOLD

SERVICES PAYABLE BY

- Workers' Compensation (including black lung benefits)
- Automobile or liability insurance
- Employer group health plans for employees and their spouses aged 65 through 69
- Employer group health plans for people entitled to Medicare solely on the basis of end-stage renal disease
- Another government program.

SERVICES

For which neither the patient nor another party on his or her behalf has a legal obligation to pay

SUPPORTIVE DEVICES FOR THE FEET

HOST'S PRESENTATION OUTLINE FOR MODULE #5
ON
FINANCES

The GOALS of Module #5 are to:

- o Provide caregiver with the tools to handle finances and financial problems more effectively;
- o Suggest financial options that may not have occurred to the caregiver.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- o Care recipient feeling - hurt, angry, resentful, scared or selfish over issue of someone else handling finances;
- o Caregiver feeling - overwhelmed at needing to learn about finances.

WELCOME AND SHARING (15 minutes)
Ask the caregivers if anyone has tried some of the mobility or bed care techniques discussed in the last module.

GUEST PRESENTATION ON FINANCES (80 minutes)
Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 156 through 164.

REFRESHMENT BREAK (10 minutes)
Plan a 10-minute break for refreshments after guest speaker(s) has talked for 40 minutes.

WRAP-UP AND SHARING (15 minutes)
Review pages 22 through 29 in AARP's turquoise Additional Resources booklet, if you are using it.

Distribute "The Most Important Thing" and collect it.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #6
ON
MANAGING THE PRESENT, PLANNING THE FUTURE

PREPARE GUEST PRESENTER

Seek guest presenter on finances from:
- Legal Counsel for Older Adults
- Local attorney experienced in issues facing older persons or
- Legal Aid Society.

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

- Confirmation Letter to Guest Presenter ______
- Joint Responsibilities of Guest Presenter and Host ______
- Tips for Group Facilitation ______
- Discussing Emotions with Caregivers ______
- Overview of "Home Is Where the Care Is" for Guest Presenter ______
- Module #6 - Detailed Outline ______
- Module #6 - Summary Outline ______
- Handouts you plan to use

  ____ ______

  ____ ______

  ____ ______

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

- Profile of Caregivers ______

OTHER PREPARATION Check when done

- Confirm meeting room logistics
  - time you will be using the facility ______
  - number of chairs you need ______
  - number of tables ______
- Plan a light, healthy refreshment ______

CS

HOST'S PRESENTATION OUTLINE FOR MODULE #6
ON
MANAGING THE PRESENT, PLANNING THE FUTURE

The GOALS of Module #6 are to:
- o Discuss ways to be good consumers of health and legal services;
- o Help caregivers, while still in this program's supportive environment, accept the present and begin making concrete plans for the future including
  - inability to continue caring for loved one at home
  - preparing for death of care recipient;
- o Provide answers and resources for legal issues.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does
- o Caregiver feeling
  - anxious or guilty about the relationship with the family doctor
  - grief as the care recipient becomes more dependent
  - guilty about resorting to nursing home care
- o Caregiver or care recipient
  - being guided in decisions only by loyalty

WELCOME AND SHARING (15 minutes)
Ask if there are any financial questions left from Module #5.

GUEST PRESENTATION ON MANAGING THE PRESENT AND PLANNING FOR THE FUTURE (80 minutes)
Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 165 through 174.

REFRESHMENT BREAK (10 minutes)
Plan a 10-minute break for refreshments after guest presenter(s) has talked for 40 minutes.

WRAP-UP AND SHARING (15 minutes)
Review pages 30 through 34 of AARP's turquoise Additional Resources booklet, if you are using it.

Distribute "The Most Important Thing" and collect it.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #7
ON
MEDICATIONS AND NUTRITION

PREPARE GUEST PRESENTER

Seek guest presenter on medications:
- o Pharmacist from local drug store, hospital, or AARP pharmacy or
- o Senior PharmD student or professor from College of Pharmacy.

Seek guest presenter on nutrition:
- o Hospital dietitian or
- o Nutritionist from American Dietetic Association, the Department of Agriculture Extension Service, or a home health agency.

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

- o Confirmation Letter to Guest Presenter _____
- o Joint Responsibilities of Guest Presenter and Host _____
- o Tips for Group Facilitation _____
- o Discussing Emotions with Caregivers _____
- o Overview of "Home Is Where the Care Is" for Guest Presenter _____
- o Module #7 Detailed Outline-Medications _____
- o Module #7 Summary Outline-Medications _____
- o Module #7 Detailed Outline-Nutrition _____
- o Module #7 Summary Outline-Nutrition _____
- o Handouts you plan to use

  ______________________________ _____

  ______________________________ _____

  ______________________________ _____

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

- o Profile of Caregivers _____

OTHER PREPARATION Check when done

- o Confirm meeting room logistics
  - time you will be using the facility _____
  - number of chairs you need _____
  - number of tables _____

- o Plan a light, healthy refreshment (ask guest presenter on nutrition for a recommendation that would fit in with the module topic) _____

HOST'S PRESENTATION OUTLINE FOR MODULE #7
ON
MEDICATIONS AND NUTRITION

The GOALS of Module #7 are to:

- o Stress the importance of the effects of medications and taking them properly
- o Provide practical tips on dealing with the nutritional problems of the care recipient.

WELCOME AND SHARING (10 minutes)
Ask caregivers if any of them has given thought as to how to continue to have some time away from their care recipient each week when this program is over

GUEST PRESENTATION ON MEDICATIONS (45 minutes)
Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 175 through 178.

REFRESHMENT BREAK (10 minutes)

GUEST PRESENTATION ON NUTRITION (45 minutes)
Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 179 through 184.

WRAP-UP AND SHARING (10 minutes)

Review pages 34 through 41 of AARP's turquoise Additional Resources booklet, if you are using it.

Distribute "The Most Important Thing" and collect it.

HOST'S PREPARATION AND CHECKLIST FOR MODULE #8
ON
FAMILY INTERACTIONS AND EMOTIONS

PREPARE GUEST PRESENTER

Seek guest presenter from:
- o Pastoral care or psychologists' group
- o Mental Health Association or
- o Gerontologist.

Using materials in "VI - Information for Guest Presenter," mail out: Check when mailed

- o Confirmation Letter to Guest Presenter ____
- o Joint Responsibilities of Guest Presenter and Host ____
- o Tips for Group Facilitation ____
- o Discussing Emotions with Caregivers ____
- o Overview of "Home Is Where the Care Is" for Guest Presenter ____
- o Module #8 Detailed Outline ____
- o Module #8 Summary Outline ____
- o Handouts you plan to use

  ____ ____

  ____ ____

  ____ ____

One week before date of presentation, both for information and as a reminder of the date, mail to guest presenter:

- o Profile of Caregivers ____

OTHER PREPARATION

Check when done

- o Confirm meeting room logistics
  - time you will be using the facility ____
  - number of chairs you need ____
  - number of tables ____
  - exercise mats for each caregiver ____
  - tape or record player with 8 minutes of slow, soft music ____

- o Plan a light, healthy refreshment ____

- o Suggested resources:
  - For each caregiver a copy of worksheets, pages 66-73:
    - o "How Are You Feeling?" ____
    - o "How is Your Care Recipient Feeling?" ____

How are YOU feeling?

Much of the stress of caregiving comes from the emotions of the situation. Inappropriate verbal responses or actions on your part might mislead others, and may cause conflict or emotional pain rather than prevent them. Being able to accurately recognize an emotion in yourself may make it easier for you to respond or act appropriately; awareness of an emotion may allow you to be less self-critical because you will see your response in the proper context of the emotional struggle also going on.

DIRECTIONS

Listed here are feelings you, as a caregiver, might have occasionally, or often. Think of situations in the past week in which each of these feelings was triggered. Then in the space provided write:

- the situation that triggered the feeling;
- whether or not you are happy with the way you responded at that time;
- how you might respond more appropriately another time.

Resentment

SITUATION____

____

HAPPY WITH RESPONSE?_______________________________

BETTER WAY TO RESPOND______________________________

____

Guilt

SITUATION____

____

HAPPY WITH RESPONSE?_______________________________

BETTER WAY TO RESPOND______________________________

____

Confidence

SITUATION____

HAPPY WITH RESPONSE?______________________________

BETTER WAY TO RESPOND_____________________________

Selfishness

SITUATION____

HAPPY WITH RESPONSE?______________________________

BETTER WAY TO RESPOND_____________________________

Happiness

SITUATION____

HAPPY WITH RESPONSE?______________________________

BETTER WAY TO RESPOND_____________________________

Cared For

SITUATION____

HAPPY WITH RESPONSE?______________________________

BETTER WAY TO RESPOND_____________________________

- Changing linens with care recipient in the bed
- Making care recipient comfortable in bed

Module #5 - Finances
- Dealing with other family members who want to help
- Taking over someone else's finances
- How to write, endorse, cash, or deposit a check
- Veterans' benefits, Social Security benefits
- Medicare/Medicaid benefits

Module #6 - Accepting the Present and Planning for the Future
- How to be a good consumer of medical services
- Learning to ask the important questions
- Knowing how to exercise your rights
- Wills
- Options for delegating decision-making power
- How to choose outside care for care recipient

Module #7 - Medications and Nutrition
- Side effects of medication
- System for taking medications more easily
- Things to know about the medications being taken
- Keeping the costs of medications down
- Nutritional needs of older persons
- Special nutritional needs of care recipient
- Making food easier to eat

Module #8 - Family Interaction and Emotions
- Relationship with outsider helping in the home
- Communicating with care recipient
- Communicating with other family members
- Understanding the emotions the care recipient and the caregiver may be feeling

Module #9 - A ninth module will be held if there is enough interest. In addition to the topics listed above, which of these would you be interested in learning about:

___Taking a blood pressure

___Taking pulse/respiration rates

___Advocating for respite care in the community

___Changing bandages/dressings

___Giving diabetic injections

___Balancing a checkbook

Other (be specific)____

____

We hope you will come away from this program with many good ideas to help make your days and nights easier, and with information on where to turn for additional assistance. We are looking forward to having you as part of this group!

Fear

SITUATION____

____

WAS FEELING APPROPRIATE?____________________________

WAY TO HELP IN FUTURE_______________________________

____

Anxiety

SITUATION____

____

WAS FEELING APPROPRIATE?____________________________

WAY TO HELP IN FUTURE_______________________________

____

Desire to Have Fun

SITUATION____

____

WAS FEELING APPROPRIATE?____________________________

WAY TO HELP IN FUTURE_______________________________

____

Homesickness

SITUATION____

____

WAS FEELING APPROPRIATE?____________________________

WAY TO HELP IN FUTURE_______________________________

____

Isolation

SITUATION ____________________

____

WAS FEELING APPROPRIATE? ____________________

WAY TO HELP IN FUTURE ____________________

____

Need for Affection

SITUATION ____________________

____

WAS FEELING APPROPRIATE? ____________________

WAY TO HELP IN FUTURE ____________________

____

Depression

SITUATION ____________________

____

WAS FEELING APPROPRIATE? ____________________

WAY TO HELP IN FUTURE ____________________

____

Resentment

SITUATION ____________________

____

WAS FEELING APPROPRIATE? ____________________

WAY TO HELP IN FUTURE ____________________

____

How is your CARE RECIPIENT feeling?

The only way to know for sure how your care recipient is feeling is to ask. If that is not practical, fill in this page with your best guess based on past experience. The important thing is to keep in mind that your care recipient has feelings too.

DIRECTIONS

Listed on these pages are feelings your care recipient may have experienced in the past week. For each one, write:

- o the situation you think,or know, triggered the feeling;
- o whether you think his or her feeling was appropriate; and
- o a way you can better help your care recipient cope with similar feelings in the future.

Embarrassment

SITUATION______________________________

____

WAS FEELING APPROPRIATE?______________________________

WAY TO HELP IN FUTURE______________________________

____

Anger

SITUATION______________________________

____

WAS FEELING APPROPRIATE?______________________________

WAY TO HELP IN FUTURE______________________________

____

Isolation

SITUATION____

____

HAPPY WITH RESPONSE?___________________________________

BETTER WAY TO RESPOND__________________________________

____

Depression

SITUATION____

____

HAPPY WITH RESPONSE?___________________________________

BETTER WAY TO RESPOND__________________________________

____

Over-protective

SITUATION ____________________

____

HAPPY WITH RESPONSE? ____________________

BETTER WAY TO RESPOND ____________________

____

Hate

SITUATION ____________________

____

HAPPY WITH RESPONSE? ____________________

BETTER WAY TO RESPOND ____________________

____

Self-delusion

SITUATION ____________________

____

HAPPY WITH RESPONSE? ____________________

BETTER WAY TO RESPOND ____________________

____

Frustration

SITUATION ____________________

____

HAPPY WITH RESPONSE? ____________________

BETTER WAY TO RESPOND ____________________

____

HOST'S PRESENTATION OUTLINE FOR MODULE #8
ON
FAMILY INTERACTIONS AND EMOTIONS

The GOALS of Module #8 are to:

- Look objectively at family relationships;
- Help caregivers recognize both their emotions and those of care recipient;
- Explore constructive ways of dealing with emotions;
- Stress the need for relaxation and teach simple relaxation techniques.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does

- Care recipient feeling
  - isolated or ignored because of poor hearing
- Caregiver feeling
  - angry or resentful toward unsupportive family members
  - guilty about not wanting to be the primary caregiver
  - angry or anxious about no longer being the dependent person
- Caregiver and care recipient feeling
  - isolated from other family members

WELCOME AND SHARING (5 minutes)

The Importance of Good Communication (5 minutes)

As a way of getting into this subject, host will read in a whisper to one caregiver the following sentence:

> As soon as Doug gets off work we are going out to dinner and maybe to a movie and would like you to join us if you are feeling well enough.

Once the caregiver has heard the sentence it should be whispered from one caregiver to the next, until the last one to hear the sentence repeats it out loud.

If it is almost exactly the same:

(1) Congratulate the caregivers for being excellent communicators;
(2) Caution that communication should never be taken for granted but needs to be continually worked at.

If the final sentence is significantly different from the original, as it usually is:

(1) Suggest this little exercise is just one example of how difficult good communication is to achieve.
(2) Caution that communication should never be taken for granted but needs to be continually worked at.

GUEST PRESENTATION ON COMMUNICATION (20 minutes)

SHARING ABOUT EMOTIONS (60 minutes including 10-minute refreshment break)

Take a refreshment break between discussion about the two handouts.

WRAP-UP WITH SHARING AND RELAXATION TECHNIQUE (30 minutes)

Outline for guest presenter to follow is located in "VI - Information for Guest Presenter" of this program material, pages 185 through 193.

HOST'S PREPARATION FOR OPTIONAL MODULE #9
ON
SPECIFIC NEEDS OF CAREGIVERS

The GOAL of Module #9 is to deal with important needs of the caregivers that were not covered in modules 1 through 8. There may be one need shared by all, or, more likely, several needs shared by only a few.

IDENTIFY WHAT THE UNMET NEEDS ARE
- o From comments written on the "Overview..."
- o From conversation with the caregivers

IDENTIFY GUEST PRESENTERS TO COVER EACH TOPIC(S)

(1) Break caregivers into small groups of the special needs
  - o Arrange for leaders and small group meeting spaces
  - o Confirm with guest presenter(s) any special set-up needs for the module

OR

(2) Arrange for caregivers to go to the resources in the community at their convenience
  - o For example, one or two of the caregivers in the group who need to learn to take a blood pressure reading can be set up with an appointment at the American Red Cross

TO PREPARE GUEST PRESENTER:

- o As appropriate, either verbally or with the written materials from this program kit, provide guest presenter with orientation as to what the caregivers have covered during "Home Is Where the Care Is."
  - Share goals of Module #9, some examples of which you will find on page 78 with possible topics
  - Be sure to stress the emphasis that was placed on watching for signs of, and discussing, the emotions surrounding any topic being covered

- o If the caregivers are meeting for the ninth time in a central location for a joint, or small group, session, one week before mail to the guest presenter(s) a copy of "Profile of Caregivers." It may need to be modified to reflect the more personal nature of dealing with a very small number of caregivers rather than the whole group.

  Include copies of any materials on the Module #9 subject that the caregivers have already received. A couple of sample handouts can be found on pages 79-80.

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TO PREPARE CAREGIVERS:

- Clarify logistics with each caregiver
- Pass on to caregivers any special instructions (clothing to wear, bring watch with second hand, etc.) from the guest presenters
- Suggest that caregiver write down in advance all the questions or concerns he or she has about the specific topic to be covered in this last session.

POSSIBLE TOPICS

LEARNING TO TAKE BLOOD PRESSURE READING

Goals

- To assist caregiver in monitoring the blood pressure for care recipient who cannot get out easily to a community resource;
- For caregiver to become proficient in taking blood pressure reading only as supplement to care recipient's professional health care;
- For caregiver to know what to do in an emergency.

TAKING PULSE AND RESPIRATION RATES

Goals

- To assist caregiver in monitoring the pulse and respiration rates for care recipient who cannot get out easily to a community resource;
- For caregiver to become proficient in taking pulse and respiration rates only as supplement to professional health care;
- For caregiver to know what to do in an emergency.

OTHER POTENTIAL TOPICS

Bandages/dressings

- wound/surgery dressing
- colostomy dressing
- bed sore dressing

Foley catheter

- how to clean it
- what to do if it leaks, clogs, slips out, or gets pulled out of place

Insulin injections

- needle safety and hygiene
- learning how to find the best spot for the injection
- what to do in an emergency

How to manage IVs

Advocating for respite care services in the community.

HOW TO TAKE A BLOOD PRESSURE READING

(NOTE: This page is only a supplement to training by a qualified instructor)

Wear very loose sleeves or sleeveless garment for practice.

Procedure:

- Position yourself so you can read blood pressure gauge at eye level
- Push or roll sleeve loosely up to top of arm; you should never take a reading over clothing
- Wrap BP cuff around upper arm, above elbow
- Take a test reading (to make sure when taking the actual reading that you do not start listening in the middle of the sounds you are hearing):
  - begin by placing fingers on wrist pulse
  - pump blood pressure cuff up until pulse stops
  - check reading on the gauge
  - quickly release air valve and let care recipient's arm rest a minute.
- Take actual reading
  - With stethescope in place over crook of elbow, inflate cuff until mercury, or needle, is just above the reading where the pulse stopped. This ensures that you will hear the very first sounds.
  - Release air steadily and take the first reading (systolic or upper number of the blood pressure) when you hear the first beating sound; take second reading (diastolic or lower number of the blood pressure reading) when you hear sound for the last time.

Points to clarify with guest presenter:

- Make sure you are clear on the effect on the blood pressure if your care recipient:
  - is standing, lying down, sitting
  - has just been exercising
- What other circumstances might affect the blood pressure reading?
- Learn what blood pressure reading requires professional assistance.

PULSE AND RESPIRATION RATES

Bring a watch with second hand to practice session.

Points that will be covered:

- Pulse points
    - Wrist
    - Neck
    - Other
- Best time to check respiration and pulse rates to get most accurate reading
- Factors that influence pulse and respiration rates.

Clarify with guest presenter what circumstances would indicate a need to call for professional help.

Directions for using page 82

LOGISTICS FOR THE PROGRAM

Fill in the blanks on this form and reproduce enough copies to mail to each caregiver who plans to attend.

The first five blanks should be filled in as follows:

We will be meeting each (day, or days, of the week)

from (starting time) to (ending time)

between (date of first program) and (date of last program)

The space labeled "Other information:" can be used, for example, to specify the easiest entrance to use, or information about proper dress in case the room is not air conditioned.

The other blanks to be filled in are self-explanatory. This form does not take the optional ninth session into account because you may not have a ninth session, and because if one is held it may be at a different location. Most caregivers will be able to make arrangements to attend the optional ninth session when those plans are finalized.

Logistics for the Program

We are very glad you will be joining us for the eight sessions of "Home Is Where the Care Is."

We will be meeting each ________________________________

from __________ to __________

between _______________ and _______________

The meeting will be at:

____
name of building where meeting will be

____
address

____
name or number of room

Parking information is: ________________________________

____

Public transportation information is: ________________________________

____

Other information: ________________________________

____

Directions for using page 84-85

CAREGIVER QUESTIONNAIRE

This questionnaire is to help you and your guest presenters target the course material specifically to the caregivers who attend your training course.

Duplicate enough copies of the questionnaire to distribute to each caregiver before the course begins.

Caregiver Questionnaire

This questionnaire and the "Overview ...," will help tailor "Home Is Where the Care Is" to meet your specific needs as much as possible. Please fill in completely. All information will be kept confidential. Please return this form and the "Overview..." on which you have marked your interests to the program host in the envelope provided by ____________.
date

Caregiver's name ______________________________

Caregiver's home address ______________________________

Caregiver's daytime phone number ______________________________

How are you related to the person you care for (your care recipient)? ____________________

Home address of care recipient ______________________________

Main illness or problem(s) of your care recipient

____

____

For what length of time has care recipient needed help?

____

How long have you provided care? ______________________________

How many hours do you spend each day providing care for your care recipient? (include the number of hours when you need to be close by in case your care recipient needs help) ____________________

Is your care recipient able to stand? ____________________

Is your care recipient able to walk alone? ____________________

Is a cane or walker required to walk? ____________________

Does your care recipient use a wheelchair all of the time?______

some of the time?_____none of the time?_____

Is your care recipient confined to bed all of the time?__________

Can your care recipient be left alone for as long as 2 1/2 hours?

____

What special diet restrictions or needs does your care recipient have, if any? ____

____

List all the medications your care recipient takes:____________

____

____

Before your care recipient became ill, who made his or her decisions?____

Is your care recipient able now to help you make decisions about his or her care? ____

Does your care recipient have a personal physician?____________

A lawyer?__________

What specific needs do you have now, or do you foresee for the near future?____

____

List other needs, concerns or interests relative to your caregiver role that you would like to have addressed during this program:

____

____

How did you find out about "Home Is Where The Care Is"?

____

Directions for using page 87-88

PROGRAM OVERVIEW FOR CAREGIVER

This overview serves at least two purposes.

- It gives the caregiver a good idea of what will be covered in the course.
- It will help you start planning the optional ninth module.

Duplicate enough copies to distribute to each caregiver before the course begins.

Program Overview for Caregiver

We are glad you will be joining us for this program. There are eight modules covering twelve subjects. An optional ninth module will be on a topic, or topics, chosen by everyone in the group. At the end of this "Overview" you can indicate the subject you would most like to see covered in the ninth module if it is held.

Module #1 - Personal Care
- Hair care, bathing, shaving
- Dental care (teeth, dentures and gums)
- Dressing
- Toilet activities
- Foot care

Module #2 - Community Resources and Time Management
- Respite care (someone to care for your family member so you can leave the house occasionally)
- Transportation assistance
- Shopping assistance
- Support groups (caregivers meet on a regular basis to provide support for each other)
- Home health aide (someone comes in to the home to assist in giving care to family member)
- Nursing home information
- Homecare equipment rental or purchase
- Services which can be performed in the home (for example, hair care, dental, etc.)
- Meals-on-Wheels (meals delivered to the home)
- Recreation
- Financial assistance
- Suggestions for improving time management

Module #3 - Home Environment and Exercise
- Ways to change the home setting for ease of care
- Ways to make the home setting safe
- Cleaning the home
- Preparing for visitors
- The importance of exercise for both the caregiver and the care recipient
- Finding time for exercise, examples of exercises

Module #4 - Mobility and Bed Care
- Coping with the problems of helping care recipient get around and aids for mobility
- Techniques for moving care recipient safely
- What to do if the care recipient falls
- How to keep the care recipient from wandering
- Preventing bed sores

Guilt

SITUATION____

WAS FEELING APPROPRIATE?____

WAY TO HELP IN FUTURE____

Directions for using page 90

INFORMATION FOR SHORT-TERM RESPITE CAREGIVER

If the caregivers who wish to attend this program cannot leave their care recipients unattended, respite care will need to be arranged.

The caregivers should provide the respite caregiver with the information on this form at a minimum. Duplicate enough copies of this form to provide at least one to each caregiver who will be arranging for respite care.

Information for Short-Term Respite Caregiver

Thank you for taking care of my ______________________________ .
relationship of care recipient

Please feel free to address him/her by the name _______________ .

His/her main health problem(s) is ______________________________

____

____ .

I will be gone ________ hours. During that time all I would
number

expect you might need to do would be: ___________________________

____

____

In case of an emergency, please contact ______________________ at
name

______________________ .
number

You will be able to reach me at ________________________________ .
number

Directions for using pages 92-93

LETTER TO GUEST PRESENTER

This is a confirmation letter to the people who will be making presentations to the caregivers.

- Retype the letter, filling in the names of the cooperating organizations, your phone number, name, and title. Leave room to sign your name also.
- Duplicate 15-20 copies of the letter.
- As each speaker is engaged, fill in the date, his or her name and presentation topic, the logistics for the day of the presentation, your signature.
- Mail it to the guest presenter with copies of these pages:

Joint Responsibilities of Guest Presenter and Host	Pg 94
Tips for Group Facilitation	Pg 95
Discussing Emotions with Caregivers	Pg 96
Overview of "Home Is Where the Care Is" for Guest Presenter	Pgs 97-98
The appropriate detailed and summary outlines	
Any handouts planned	

(Date)

Dear :

Thank you for agreeing to make a small-group presentation on the subject of ______________________________ for "Home Is Where The Care Is," a eight-module course being offered by:

____

____

____

Each caregiver taking this course is caring in the home for a chronically ill, disabled or frail older family member or close friend, mostly without the benefit of any formal training in providing care.

For your orientation I have enclosed "Overview - Home Is Where The Care Is," a list of subjects being covered in all the modules.

The goals of this program are to:
- Leave the caregivers with helpful tips and ideas to implement immediately; and
- Leave the caregivers with knowledge about resources to turn to when other questions and problems arise after the course is over.

The emphases of this program are on helping:
- The caregiver see that he or she is not alone in the task of caregiving;
- The care recipient stay as independent as possible; and
- The caregiver take care of himself or herself both physically and emotionally.

To make your presentation as easy for you as possible, and to prevent overlap between guest presenters, I have enclosed a detailed outline, and a summarized version, of the information we hope you will cover. It was created by talking with caregivers, care recipients, and other professionals like you about the needs of caregivers. In addition to the material in this outline, please feel free to add from your own experience, including specifics for this geographic area.

Because getting the caregivers to share about their problems and feelings is a major part of this course, your outline includes information on some emotions you might encounter with the group. I have enclosed two other items for your orientation, "Tips For Group Facilitation" and "Discussing Emotions with Caregivers." There is a sample of the handouts we are planning for that day. Please feel free to bring any that you feel are important also, although we are trying not to inundate the caregivers with material they may only feel guilty about not reading.

Logistics for that day are:

day and date ______________________________

location ______________________________

time program begins ______________________________

time your presentation is expected to begin ____________

length of presentation (including questions and answers)

____

parking information ______________________________

____

If you have any questions feel free to call me at ____________.

I know your time is valuable and I greatly appreciate your willingness to speak to these caregivers. We look forward to your presentation.

Sincerely,

(Your Name)

(Your Title)

Enclosures:
- Joint Responsibilities of Guest Presenter and Host
- Tips for Group Facilitation
- Discussing Emotions with Caregivers
- Overview - Home Is Where the Care Is
- Detailed and summary outlines
- Handouts for the module

Joint Responsibilities of Guest Presenter and Host

During each module presentation the guest presenter and host should:

- Be sensitive to the needs of both the caregivers and the care recipients;
- Divide the available discussion time between factual information and the emotions the caregivers may be feeling;
- Promote good small group dynamics:
  - Make people feel comfortable;
  - Be good at both listening and helping people express themselves;
  - Ensure everyone a chance to be involved;
  - Be flexible enough for a conversation to follow an unexpected twist if it is obviously important to the caregivers, without totally losing the subject at hand;
- Be relaxed and reassuring; allow humor to surface for and among the caregivers;
- Be prepared to work into the outline any unique resources available in the community such as audiovisuals available from the county library (be sure to preview first), model outreach programs, university offerings, etc.

Tips for Group Facilitation

Knowing something about group process could be a key to making "Home Is Where the Care Is" very successful. Every caregiver needs to feel important and be a part of the group during each module; every caregiver needs to feel that what he or she has to say is very important. To accomplish this the host and guest presenter should concentrate on the following.

PRACTICE GOOD LISTENING SKILLS

- Don't try to do anything else while a caregiver is talking; give undivided attention.
- If you think of something important to say while listening, jot down a key word as a reminder so you can share the thought later without interrupting the caregiver.
- If you don't understand or notice that someone else doesn't understand what a caregiver has said, ask for clarification; someone else may be unclear but not want to admit it.

ENCOURAGE OPEN DISCUSSION

- No concern voiced by a caregiver is unimportant; make sure a supportive, not judgmental, response is the last thing said to the caregiver so that person will continue to feel comfortable sharing.
- On a given topic, ask caregivers for examples or ideas based on their own experience.
- Encourage a caregiver to share a thought completely with a brief comment ("Uh-huh", "I see") or nod of the head without interrupting the caregiver's train of thought.
- If sharing on a subject would be valuable to the group but difficult due to the caregiver having to make himself or herself vulnerable, ask that each person share but that no one respond; host can let caregivers feel they have been heard with a supportive comment which neither judges nor belittles anything that has been said.
- Make sure that each caregiver gets help with specific problems to encourage that caregiver to jump into the conversation more often.

PREVENT ONE CAREGIVER FROM MONOPOLIZING THE DISCUSSION

- To politely cut off a caregiver who is straying from the subject try, "It seems you have a variety of concerns; let's talk about ______________________ a bit later."
- When it is time to get feedback from the caregivers, don't ask the most talkative one to respond first.
- Politely interrupt the talkative caregiver to ask another caregiver if she or he has had a similar experience.

Discussing Emotions with Caregivers

The emotions listed at the beginning of each module and inserted in different type in the outline are ones common to caregiving. However, caregivers may not always be aware of what is happening to them, and to their care recipients, emotionally.

Since being aware of emotions usually makes situations easier to cope with or tolerate, the goal of the host and guest presenter during each module should be to help caregivers:

- Recognize the emotions they and the care recipient are feeling;
- Realize those feelings are quite normal and acceptable;
- Find ways that the negative feelings can be handled and turned into a more positive experience.
- Feel good about constructive ways they have already discovered to deal with emotionally charged issues.

Working the emotions into the outline presentation:

Listen to what the caregivers are saying and asking. If an emotion is mentioned, pick up on that and talk about it briefly. If emotions are not being shared easily, ask if anyone is feeling angry, resentful, grateful, guilty, etc.

As an example, if you are going over the Community Resources you might pose a question to the caregivers such as, "Do you think the care recipient might be feeling isolated?" If the answer is yes, promote some of the appropriate community resources, such as an adult day care center or a senior citizens center. If the answer is no, ask "Why?" Help the caregiver see that almost everyone has a need for other people and stimulation, for a variety of reasons.

Mention to the host if you feel an important emotion has been skipped during a module; the eighth module may allow time to come back to it.

Overview for Guest Presenter

We are glad you will be making a presentation for this program. There are eight regular modules and a ninth optional one. This overview will give you an idea of what topics other guest presenters have covered, or will be covering.

Module #1 - Personal Care
- o Hair care, bathing, shaving
- o Dental care (teeth, dentures and gums)
- o Dressing
- o Toilet activities
- o Foot care

Module #2 - Community Resources and Time Management
- o Respite care (someone to care for your family member so you can leave the house occasionally)
- o Transportation assistance
- o Shopping assistance
- o Support groups (caregivers meet on a regular basis to provide support for each other)
- o Home health aide (someone comes in to the home to assist in giving care to family member)
- o Nursing home information
- o Homecare equipment rental or purchase
- o Services which can be performed in the home (for example, hair care, dental, etc.)
- o Meals-on-Wheels (meals delivered to the home)
- o Recreation
- o Financial assistance
- o Suggestions for improving time management

Module #3 - Home Environment and Exercise
- o Ways to change the home setting for ease of care
- o Ways to make the home setting safe
- o Cleaning the home
- o Preparing for visitors
- o The importance of exercise for both the caregiver and the care recipient
- o Finding time for exercise, examples of exercises

Module #4 - Mobility and Bed Care
- o Coping with the problems of helping care recipient get around and aids for mobility
- o Techniques for moving care recipient safely
- o What to do if the care recipient falls
- o How to keep the care recipient from wandering
- o Preventing bed sores
- o Changing linens with care recipient in the bed

- Making care recipient comfortable in bed

Module #5 - Finances
- Dealing with other family members who want to help
- Taking over someone else's finances
- How to write, endorse, cash, or deposit a check
- Veterans' benefits, Social Security benefits
- Medicare/Medicaid benefits

Module #6 - Accepting the Present and Planning for the Future
- How to be a good consumer of medical services
- Learning to ask the important questions
- Knowing how to exercise your rights
- Wills
- Options for delegating decision-making power
- How to choose outside care for care recipient

Module #7 - Medications and Nutrition
- Side effects of medication
- System for taking medications more easily
- Things to know about the medications being taken
- Keeping the costs of medications down
- Nutritional needs of older persons
- Special nutritional needs of care recipient
- Making food easier to eat
- Dealing with special diets

Module #8 - Family Interaction and Other Emotions
- Relationship with outsider helping in the home
- Communicating with care recipient
- Communicating with other family members
- Understanding the emotions the care recipient may be feeling
- Understanding the emotions the caregiver may be feeling

Module #9

The topic of the ninth module is yet to be decided. In addition to the topics listed above, these are topics that may be covered:

- Blood pressure reading
- Pulse and respiration rates
- Bandages and dressings
- Diabetic injections
- Balancing a checkbook
- Advocating for respite care in the community

We hope the caregivers will come away from this program with many good ideas to help make their days and nights easier, and with information on where to turn for additional assistance. We are looking forward to your contribution to this goal!

Directions for using pages 100-101

PROFILE OF CAREGIVERS

This form serves two purposes:

- To provide guest presenter with specific information about the caregivers in this group in order to make his or her presentation as applicable as possible
- To serve as a reminder of the date of the presentation

After the Caregiver Questionnaires are turned in, fill in all the information about the caregivers on one copy of this letter and duplicate 15 or so copies.

One week before each module, personalize a copy of the letter for each guest presenter by filling in the date, his or her name, the date and time of the presentation, and your signature.

Dear :

We look forward to hearing your presentation for "Home Is Where the Care Is" on ______________ at ________.
date time

Some of this information about the caregivers you will be speaking to, and their care recipients, may help you make your presentation more specific in terms of:

o Topics to emphasize;
o Additional resources you may want to recommend;
o Questions you may want to pose to caregivers.

The number of caregivers in the group:______

The relationship the care recipients are to the caregivers:

____

____

The main illnesses or problem(s) of the care recipients are:

____

____

____

____

The length of time the care recipients have needed help:

from ______ yrs to ______ yrs

The length of time the caregivers have provided that care:

from ______ yrs to ______ yrs

The number of hours caregivers spend each day providing care (including the number of hours when they need to be close by in case their care recipient needs help):

from ______ hrs to ______ hrs a day

The number of care recipients: able to stand alone __________

able to walk alone __________

requiring a cane or walker to walk __________

using a wheelchair all ____ some ____ none ____ of the time

confined to bed all of the time __________

who can be left alone for as long as 2 1/2 hours __________

Special diet restrictions the care recipients have:

____

____

____

Medications the care recipients are taking: ______________

____

____

____

____

____

The number of care recipients who are able to participate in decision making about their care: ______

The number of care recipients with personal physicians: ______

The number of care recipients with lawyers: ______

We look forward to seeing you.

Sincerely,

GUEST PRESENTER'S PRESENTATION OUTLINE FOR MODULE #1
ON
PERSONAL CARE

The GOALS of Module #1 are to:

- Begin helping caregivers get acquainted with each other and have caregivers share a little about themselves;
- Impress upon caregivers the importance of helping their care recipients remain as independent as possible;
- Provide tips to make personal care easier;
- Deal with the emotional aspects of personal care.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Caregiver feeling
    - unloved or unappreciated for all the work being done;
    - guilty over stretching the truth to accomplish a goal;
    - embarrassed and ashamed of feelings about toilet issues;
    - like a failure for inability to cope;
    - proud over helping care recipient be independent;
- Care recipient feeling
    - embarrassed and ashamed of feelings about toilet issues;
    - sense of loss in new situation;
    - depressed over self-image.

NOTE: Remember that in the next module the main topic is community resources. The sources of many of the aids and services you mention this session for personal care will be pointed out in the next session.

PERSONAL CARE (70 minutes not including 10-minute refreshment break)

A major goal of caregiver should be for care recipient to provide as much of his or her own personal care as possible for as long as possible.

Caregiver should be feeling PROUD that she or he does maybe even less for care recipient now than before the illness.

Caregiver should not hover and try to do everything for care recipient. Treat care recipient as normally as possible. Realize what a wonderful gift it is to let the care recipient do things on his or her own, even if it is a struggle. Care recipient still needs his or her own independence and dignity, still wants a freedom of choice that everyone else cherishes, still needs to feel useful and feel the joy of accomplishment, even if on a smaller scale than before. When something does have to be done for care recipient, try not to draw attention to it.

Hair Care (5 minutes)

- Importance of keeping hair clean and neat
  - Physical aspects
    - To keep germs/bacteria under control
    - To keep scalp from getting irritated
  - Mental health aspects
    - If hair is clean and trim, person's self-image is usually better
      - Important for women and men
      - Having hair done goes with having fun, which care recipients should continue to do

Care recipient may be feeling tremendous SENSE OF LOSS

Care recipient might feel greater loss over "small" things than caregiver realizes. For women, having to give up going to a religious service or getting their hair done could be major, not minor, concessions. Women also seem to be most affected if they have to leave their own home to live somewhere else. For men, giving up their car, even if they are no longer able to drive it, might be most painful.

Caregiver simply needs to be aware of the impact of losses on care recipient, and to the extent possible, let care recipient be in on decisions and choices. Don't assume you know what is best for the care recipient if you can ask to be sure.

Care recipient may be feeling DEPRESSED

The care recipient's need to laugh and have fun goes on. Part of that fun is related to appearance. Keep mirrors around to encourage the care recipient to want to look as nice as possible. Consider the potential boost to the care recipient's spirits as a result of a new article of clothing or a trip to the hairdresser.

- Hair care techniques/aids
  - For ease of care
    - A permanent might make hair care easier
      - Use most gentle solution to prevent damage to skin which may be sensitive
      - Some medications make skin sensitive
    - Dry shampoo in between shampooing with water
      - "Shampoo" powder is sprinkled on and combed out
  - For partially ambulatory care recipient
    - Some beauty/barber salons will be better equipped than others to take handicapped patrons
  - For less expensive care
    - Beauticians and barbers still in school usually charge less for shampoos and cuts
  - For bed-bound care recipient

    - Some beauticians/barbers make house calls
    - One can obtain a basin with head rest for use in bed

Dental Care (15 minutes)

- Nutritional component
  - Teeth need to be pain-free, gums need to be healthy, and dentures need to fit well, or care recipient may have trouble eating
- Mental health aspect
  - If mouth feels dirty, breath feels bad, or teeth look bad, care recipient will have a poorer self-image
- General care
  - Teeth should be brushed twice a day
  - If care recipient has no teeth or dentures, gums and mouth still need cleaning
  - If care recipient is on medication that dries the mouth out, ask physician for artificial saliva; saliva is part of the natural process of cleansing the mouth and aiding digestion. Medications that dry mouth may include: antidepressants, anti-anxiety agents, antihistamines, diuretics, and antihypertensives.
  - Topical sodium fluoride rinses can be purchased over-the-counter in grocery or drug stores and can be used to help prevent tooth decay
  - A rinse of 1/2 teaspoon hydrogen peroxide, 2 tablespoons baking soda and 3 shakes of salt, diluted with more hydrogen peroxide and just a little water is a good antiseptic for any mouth (unless care recipient is on sodium-free diet)
    - Helps prevent sores in the mouth of persons undergoing chemotherapy
    - Is harmless if swallowed
- Care of teeth
  - If care recipient is brushing own teeth
    - Caregiver should check to make sure that the brushing continues to be effective
    - Utensils for brushing teeth from bed
      - Small container with water to wet toothbrush and later to spit into
      - Toothbrush and toothpaste
      - Cup with barely salted water to rinse mouth out
      - Mouthwash if desired
  - If caregiver needs to brush care recipient's teeth
    - A longer handled brush, angled end brush, sturdy swab-like stick with spongy tip called "toothette" or, last resort, toothpaste on fingers may be easier to use
    - Mentally divide teeth into four sections
      - Brush inside, tooth surface and outside of each section in turn
      - Be sure to massage the gums with the brush

- Use dental floss once a day and especially if food is wedged in between teeth
  - To prevent damage to gums with the floss, see-saw the floss back and forth to get it between the teeth, rather than forcing floss straight toward the gum

- If care recipient is not cooperative
  - Be patient
  - Explain exactly what you are going to do when you brush care recipient's teeth
    - If care recipient has dementia, point and/or demonstrate what you are going to do
  - Brush the teeth during the best, most receptive part of the care recipient's day
  - If care recipient won't/can't spit out toothpaste, brush with a paste made of 1/2 teaspoon hydrogen peroxide, 2 tablespoons baking soda and 3 shakes of salt, which will be harmless if swallowed

- Denture care
  - Dentures should be checked occasionally for proper fit, especially after a weight loss
  - When dentures are out of the mouth they should be kept in water
  - Help care recipient care for own dentures as long as possible
    - If care recipient forgets to use cleaning tablet at night, set tablet out as a reminder
    - If care recipient forgets to change the cleaning water, dump the old out as a reminder that new water is needed (let care recipient put the clean water in)
  - If care recipient cannot care for dentures, for the caregiver who is squeamish about touching someone else's dirty dentures:
    - Have care recipient release dentures into a cup partially filled with warm water
    - Run warm, not hot, water over the dentures to rinse saliva and denture adhesive off before touching them
    - Put them in water with cleaning tablet to soak
    - Rinse them with warm water over a basin filled with water (to cushion the dentures should they be dropped) and using a denture brush, clean away any remaining particles
    - Apply denture adhesive according to package directions
    - Reinsert into care recipient's mouth
- Care of gums if care recipient has no teeth
  - To keep gums in better tone, condition and free of bacteria
    - Brush gums two times a day with soft tooth brush
      - One of those times sprinkle a little salt on the wet brush first, covered with thin smear of toothpaste if desired

        - Massage gums once a day
- Dental emergencies for homebound care recipients
    - Some dentists make housecalls

10-MINUTE REFRESHMENT BREAK

Bathing (15 minutes)

- Reasons for bathing
    - Hygiene
        - Personal hygiene may deteriorate with age simply because of senses becoming less acute; illness could compound this problem
        - Baths are necessary to rid body of bacteria, some of which are responsible for body odor
        - Acids formed by body wastes irritate the skin and make it more susceptible to breakdown and pressure sores
    - Check condition of skin
        - Watch for sores, rashes, change in skin color or anything else out of the ordinary to report to the doctor
    - Exercise
        - Use bath time to do range-of-motion exercises
- Sponge bath tips
    - When to use sponge bath
        - When care recipient is bed-bound
        - A couple of times a week along with two full baths (too many baths will dry skin)
        - When getting care recipient in and out of bath tub or shower is too difficult
    - How to give sponge bath
        - While care recipient is standing, sitting, or lying
        - Wash one area, rinse well, dry and cover it up before going on to next area to prevent care recipient from catching cold
            - Soap residue might irritate the skin making it more susceptible to pressure sores
- Ideas for after any bath
    - Dry off with hair dryer, especially hard to dry areas like behind the ears and knees, under the arms and breasts, between the toes, in the crotch
        - Moisture might irritate the skin making it more susceptible to pressure sores
    - Wrap care recipient in over-sized terry cloth robe for both immediate warmth and absorption
        - Cover care recipient with cotton flannel sheet for same purpose
    - Rub moisturizing lotion in well, wipe off excess with soft cloth
        - To prevent drying of skin and to decrease the possibility of pressure sores

        - For the physical and mental health benefits to the care recipient of the body massage
- Aids for bathing
    - Helping to preserve care recipient's independence and dignity by continuing use of bathroom
        - Install bars for holding on to in bathtub or shower stall
        - Put seat in bathtub, or raise the floor level of the tub if getting the care recipient down in and back up out of the tub is difficult
            - Hoists are available to lift care recipient in and out of tub
        - In a shower stall using a lawn grid chair without a chair pad and a long shower hose, caregiver can get soap and water over care recipient's entire body without care recipient having to stand
        - Attaching a long shower hose, with cut off switch at spray head
        - If there is a question as to whether or not care recipient is still bathing self, check to see if bath towel is being used
- Dealing with resistance to bathing
    - Can become a major problem, especially if care recipient suffers from dementia
        - Try to figure out what is causing the resistance
            - Fear of the water or of falling
            - Embarrassment over having someone help with the bath/shower
            - Embarrassment over having to be bathed by a person of the opposite sex
        - Do whatever is necessary to get care recipient to bathe

> Caregiver may be feeling GUILTY
>
> Sometimes caregiver will be right about what is best and care recipient may resist. If the only way to get care recipient to go along is to stretch the truth somewhat, caregiver should not feel badly.

            - Put a chair in the shower stall
            - Add rails to hang on to
            - Try a bath instead of a shower, or vice versa
            - At the swimming pool, do the shower with care recipient's bathing suit on
                - Make sure genital area is still washed, even if it means reaching inside the suit

        - Get a "stranger" to help with the bath (sometimes care recipient will absolutely not bathe for family member but will for someone else) like a home health aide
        - Ask home health service to send aide of same sex as your care recipient for bath time
        - Tell care recipient it is "Saturday"

Dressing (10 minutes)

- Importance of being dressed
    - Mental health considerations
        - For care recipient's self-image she or he should be dressed every day
            - Don't set the mood and appearance of illness by having the care recipient in pajamas and/or robe all the time
            - Helps preserve care recipient's dignity
        - For caregiver's morale, caregiver will feel better if she or he is looking at a nicely dressed care recipient all of the time, even if it is more work
- Task of getting dressed
    - Practical considerations
        - Care recipient may be more self-sufficient if someone is not right there to help

Caregiver may be feeling EMBARRASSED

If care recipient is dressing himself or herself but gets clothes buttoned incorrectly, on backwards or chooses clothes which go horribly together, caregiver may feel embarrassed or worry that people will think care recipient is not being well taken care of.

Caregiver needs to decide which is most important - the end result so the outside world can see the care recipient is well cared for, or the accomplishment of the care recipient continuing to dress with little or no assistance.

        - Adaptations so care recipient can dress himself or herself for as long as possible
            - Enlarge buttonholes and sew on larger buttons
            - Use clothing with no, or easier, fasteners

Care recipient may be feeling DISCOURAGED

Care recipient is aware that she or he can't do things as well or as quickly as in the past, and does not need to be reminded of it. Hold back on negative comments to the care recipient, and look for things to praise. The taste of success from a small task that the care recipient is able to do, even if it takes longer or is not done perfectly, may give an important boost in self-confidence or self-worth.

      - Warm-up suits (sweat pants) are warm and comfortable; the pants will have an elastic waistband
      - Slip-on shoes and slippers
      - Tennis shoes with velcro fasteners
      - Clothes with front or velcro fasteners
    - Make concessions from traditional way of dressing; care recipient can give up always wearing a tie, for example
  - Helping, or dressing, a care recipient who is partially or totally immobile
    - For a wheelchair-bound care recipient who is very difficult to move, cut the seat out of pants so the legs, front and sides of the hips can easily be clothed; velcro fastener on the waistband of the pants at the cut edges can fasten onto the back of the wheelchair seat; top with a shirt/blouse that comes down past the waist
    - Use a skirt gathered on a plastic band (most often seen on aprons) and open down the back; slip band around care recipient's waist and arrange fabric to cover hips and legs
    - For a stroke victim, dress the affected side first. Don't call it the "bad" side, call it the right or left side. It is better for care recipient's self-image if there is no "bad" part of his or her body.
    - Find positioning that will be safe for both care recipient and caregiver for putting pants on someone who can't stand alone
      - Slip pants on to above the knees
      - Pull up rest of the way in a place where weight of care recipient does not have to be on caregiver
        - Standing from toilet seat where care recipient can brace self with bar installed there
        - Behind an overstuffed chair where care recipient can rest upper torso over back of chair
- Aesthetic considerations
  - For special occasions consider taking a favorite dress or shirt of care recipient's and altering it for the new circumstances
    - Permanently close the button front
    - Make a cut up the back and attach ties
      - Garment can be slipped on from the front
  - If care recipient insists on wearing the same clothes over and over again

- Perhaps poor eyesight plays a role. Care recipient knows one outfit is okay to wear; poor eyesight may prevent him or her from choosing something else to wear that is equally okay
- Caregiver should share with care recipient that she or he does not want others to think care recipient isn't being well cared for and loved because of wearing the same clothing every day
- Mention a special friend of the care recipient's who wears different clothes each day
- Invest in a second identical set of clothing so one set can be in the laundry
- Plan to do laundry anytime that care recipient will have to be out of the clothing
  - At bedtime
  - For a swim class
  - For a bath
- Have someone care recipient particularly likes mention profusely how good the care recipient also looks in at least two other outfits. (Care recipient will often do things for others that she or he won't do for caregiver)

Toilet activities (20 minutes)

- Help care recipient use bathroom on own for as long as possible
  - Install bar on wall by toilet. Towel rod is not a good substitute
  - Use upward extension of toilet seat
  - Install an emergency call button or bell to ring
  - Remove door molding so wheelchair/walker can get in
- If care recipient is using bathroom on own but misses the toilet bowl
  - It might be a vision problem
    - Create contrasting colors between floor and fixtures with rug, or seat or tank covers
  - Protect rug or floor area around toilet
    - Cut out of newspaper a pattern that fits around base of toilet
      - Using pattern, cut floor protectors out of something easy to cut, relatively durable, and cheap to replace, such as leftover wallpaper from friends or wallpaper stores
- Moving the bathroom to the bedside
  - A bed pan on a chair by the bed might be easier than using a bedpan in the bed
  - Urinals available for both men and women
  - Prepare a bedside commode
    - Be discreet about need for commode
      - Some convert to regular chairs
    - Commodes need to be against wall or heavy furniture to reduce tendency to tip

- Do not leave throw rug under commode
  - To keep it clean
  - To prevent odor of urine in the room
  - To prevent tripping
- To protect floor or carpet and aid clean-up
  - Put plastic under the chair or commode (drop cloths, plastic bags from the dry cleaners or large plastic bags used by clothing and variety stores)
  - Cover plastic with newspapers
    - Newspapers will also prevent feet from slipping as easily
  - Replace newspapers at soon as they are dirty
- Put some water in the commode to dilute the urine and decrease the odor
- Empty immediately after use

- Moving the bathroom to another room
  - If regular bathroom is difficult for care recipient to use because of its size or location, put portable commode in another room
    - Utility room
    - Guest room
    - Side or back entry hall to home
  - Put signs on door labeling it as a bathroom
  - Do whatever else needs to be done to ensure its privacy for care recipient (for example, locking second door to the makeshift bathroom)
- Incontinence
  - Degrees and causes of incontinence
    - Care recipient should be evaluated by physician in case incontinence is reversible with treatment
    - Care recipient may be incontinent at home with family but not while out with friends, like at a day care center for example
  - Dealing with incontinence
    - Scheduling trips to bathroom
      - Keep track of when care recipient eats and drinks, and eliminates for 2-3 days
      - Based on pattern you see, schedule trips to bathroom just in advance of when your care recipient might be incontinent
    - If care recipient resists using pants shields or protectors (do not refer to them as diapers)
      - Be understanding
      - Try to help him or her see how using them increases independence by not being tied to a bathroom
      - Try to convey how using them will mean less chance of embarrassment
      - You may simply have to be firm and tell your care recipient he or she has to wear them

- o Accommodate disorientation rather than fight it
  - Put bells on the bathroom door so care recipient can remember which room is the bathroom
  - Put signs and arrows on wall leading to bathroom
  - If care recipient tries to use another room as the bathroom (such as a closet)
    - o Bar door to see if that gets care recipient back to real bathroom
    - o Set up chosen room as a bathroom
      - Remove everything from the closet
      - Line the floor and lower half of the wall with plastic, or plastic coated wallpaper that can be easily cleaned
      - Put a pail on the floor, or a portable commode in closet

Care recipient and caregiver may be feeling EMBARRASSED

If the care recipient is incontinent, or bed-bound and cannot make it to the bathroom, the issue of toilet habits may be very difficult for both, especially if the caregiver is a child of care recipient and not a spouse.

Caregiver needs to be matter of fact and good-natured about the subject; kidding around might ease pain somewhat; having other things to talk about might be a helpful distraction. If caregiver is the child of the care recipient, remind the care recipient that when caregiver was a child the parent had this task. Now the tables are just turned. Be discreet about the problem; don't mention it in front of company, keep equipment and supplies out of sight, don't put crisp plastic on the bed that will make tell-tale noise every time the care recipient moves.

Caregiver may be feeling ASHAMED

Knowing that bodily functions are necessary and normal, and that it is not the care recipient's fault if he or she is incontinent does not make it any easier for the caregiver to cope. The caregiver may feel ashamed that this issue is disgusting to him or her, and that the caregiver does not want to deal with it.

Caregiver may be feeling like a FAILURE

Cleaning up after and dealing with incontinence are not pleasant tasks. The issue of incontinence is one of the two most common breaking points for a caregiver. Anyone who is a parent can remember the relief when the child was finally potty trained; this situation is the reverse.

Utilize all the tips for coping; seek help from the home health aide whenever possible; if that isn't enough, caregiver may need to admit that she or he cannot care for the care recipient alone. If the care recipient needs to be moved out of the home for care, caregiver should not feel like a failure. All caregivers will not be perfect at coping with all situations, just as no one person is good at all other jobs in the world. Where one caregiver has had a strength in managing a particular situation, another caregiver has not, and vice versa.

- If care recipient is bed-bound
  - Urinals for men and women
    - Offer its use every 1 1/2 to 2 hours
  - Doctor may need to begin use of catheter
    - Tube to drain off urine as it collects in bladder
    - Request externally applied catheter for male care recipient
      - Called condom, or Texas, catheter
      - Less chance of creating infection than catheter which is inserted into the urethra
- Protecting the bed
  - Changing protectors on the bed is easier than changing the whole bed
  - Options
    - Rubber sheet under the bed sheet
    - Garbage bag opened out
    - Flannel covered rubber available by the yard in fabric stores
      - Does not make noise when care recipient moves in bed
    - Disposable bed pads available in large quantities
- Bowel movements
  - Planning to take place in bed for the bed-bound care recipient, for one who is afraid to sit on the toilet, or for one who is too difficult to take often to the bathroom
    - To make cleaning up easier
      - Don't use bedpan
      - Position care recipient on his or her side
      - Spread disposable plastic lined protector under care recipient's hips
  - Suppositories
    - Take a couple of hours to begin working
    - Occupy care recipient in bed during that time rather than just waiting
      - Feed care recipient a meal
      - Brush care recipient's teeth
    - Then turn care recipient to side and position plastic-lined bed protector

    - Adjust schedule for the convenience of the caregiver if bowel movements are regular but come at an inconvenient time
        - Care recipient eats lunch each day at 1PM
        - Bowel movement occurs at 4PM
        - Home health aide is there from 2:30-3:30
        - Serve lunch at noon so bowel movement will occur when aide is there to assist
- Cleanliness
    - To prevent spread of germs
    - To prevent odors in the home
    - Wash hands frequently with soap and under running water after handling any toilet articles and before doing anything in the kitchen
    - Use thin plastic gloves
        - To protect caregiver from germs and bacteria
        - To make dealing with toilet articles a little less unpleasant
        - Available from medical supply houses, drug stores, or paint stores

Foot care (2 minutes)

- Check with physician for recommendations
    - Especially important for diabetics who have decreased blood circulation to their feet
- Skin care
    - Dry completely after bathing, especially between toes
        - To prevent fungal growth
        - To decrease irritation
            - Can use hair dryer on lowest setting for easier drying
    - Rub lotion on to keep skin from cracking
        - Sores on feet are slower to heal because of poorer blood circulation
- Toenail care
    - Clip nails only after they are softened by soaking in the bathtub or a foot bath
    - Leave no sharp corners on nails which might cut into the adjoining toe

Shaving (3 minutes)

- Safety razor
    - Soften beard and clean oils off face before shaving by washing face with soap and water
    - Apply thin layer of shaving cream
    - Pull skin tight to smooth wrinkles so blade doesn't nick skin
        - Shave down on cheeks and chin
        - Shave up on neck
    - Wipe off excess shaving cream with warm damp cloth, pat face dry, rub face with skin cream not containing alcohol. Avoid after shave lotion containing alcohol which will dry the skin.

- Electric shaver
    - Soften beard and clean oils off face before shaving by washing face with soap and water
    - Pat face dry
    - After shaving rub face with skin cream not containing alcohol. Avoid after shave lotion containing alcohol which will dry the skin.

SUMMARY FOR PRESENTATION OF MODULE #1
ON
PERSONAL CARE

GOALS
- o Help caregivers get acquainted
- o Impress upon caregiver the importance of the care recipient's self-sufficiency
- o Provide tips to make personal care easier
- o Deal with the emotional aspects of personal care

EMOTIONS
- o Caregiver feeling
  - unloved or unappreciated
  - proud
  - guilty
  - like a failure
- o Caregiver and care recipient feeling embarrassed
- o Care recipient feeling
  - sense of loss
  - depressed
  - ashamed of feelings

GETTING ACQUAINTED (35 minutes)

PERSONAL CARE (70 MINUTES with 10-minute break for refreshments)

Goal
- o Care recipient to care for self as much as possible

- o Hair care (5 minutes)
  - Importance of keeping hair clean and neat
    - o Physical aspects
    - o Mental health aspects
  - Hair care techniques and aids

- o Dental Care (15 minutes)
  - Nutritional component
  - Mental health aspect
  - General care
  - Teeth
    - o If care recipient is brushing
    - o If caregiver needs to brush for care recipient
    - o If care recipient is not cooperative
  - Dentures
    - o Check for fit
    - o Care recipient caring for own dentures
    - o Caregiver caring for the dentures
  - Care of gums
  - Dental emergencies

REFRESHMENTS (10 minutes)

- Bathing (15 minutes)
  - Reasons for bathing
    - Hygiene
    - Check condition of skin
    - Exercise
  - Sponge bath tips
    - When to use
    - How to give
  - Ideas for after any bath
    - Hair dryer
    - Terry cloth robe
    - Cotton flannel sheets
    - Moisturizing lotion
  - Aids for bathing
    - Preserving care recipient's independence and dignity
  - Resistance to bathing

- Dressing (10 minutes)
  - Importance of being dressed
    - Mental health
  - Task of getting dressed
    - Adaptations so care recipient can dress self
    - Helping immobile care recipient
      - Altered clothes
      - Safe and easy positioning for both caregiver and care recipient
  - Aesthetic considerations
    - Special occasions
    - Preventing wearing of the same clothes

- Toilet activities (20 minutes)
  - Help care recipient use bathroom for as long as possible
    - Aids in bathroom
    - Protection and cleanup
  - Moving bathroom to bedside
    - Bedpan
    - Urinals
    - Commodes
      - Safety considerations
  - Setting up bathroom in another room
  - Incontinence
    - Check with physician
    - Dealing with irreversible incontinence
      - Scheduling trips to bathroom
      - Pants shields
      - Accommodating disorientation
      - Bed-bound care recipient
    - Protecting the bed
  - Bowel movements
    - Planning for it to take place in bed
    - Using suppository
    - Scheduling for convenience of caregiver

    - Cleanliness
        - Washing hands
        - Plastic gloves

- Foot Care (2 minutes)
    - Physician recommendations
    - Skin care
    - Toenail care

- Shaving (3 minutes)
    - Safety razor
    - Electric shaver

GUEST PRESENTER'S PRESENTATION OUTLINE FOR MODULE #2
ON
COMMUNITY RESOURCES

The GOALS of Module #2 are to:

- Discuss community and other resources that caregivers might begin using immediately;
- Have caregivers share experiences with resources they have already tried;
- Help caregivers feel comfortable seeking and accepting assistance;

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Caregiver feeling
  - overwhelmed by job to be done;
  - uncomfortable using community resources;
  - resentful of time caregiving takes;
  - burned out;
- Care recipient feeling
  - isolated;
  - self-pity;
  - dissatisfied with living situation.

GETTING ACQUAINTED WITH COMMUNITY RESOURCES (65 minutes)

(After 40 minutes, take 10-minute refreshment break)

Review Community Resources booklet together in as much detail as time allows:

- Resources to include:
  - Emergency numbers
  - General information numbers
    - Area Agency on Aging
    - Information and Referral
    - Health department
    - Library
    - Veterans Administration
  - Food services
    - Dining sites
    - Meals-on-Wheels
    - Grocery stores that deliver
    - Shopping aids
    - Nutrition counseling
  - Transportation services
  - Medical services
    - Drugstores with special services
    - Dental care
    - Home health aide
    - Emergency care clinics
    - Home health and medical care supplies
  - Household services

  - Hair care
  - Safety
  - Chore and errand service
- Support services
  - Companion services
  - Telephone reassurance
  - Case management
  - Personal Emergency Response Systems
  - Adult day care centers
  - Respite care
  - Support groups
  - Handicapped organizations
  - Counseling services
- National organizations
  - The disease-specific organizations relevant to these caregivers such as the American Heart Association, American Diabetes Association, American Cancer Society, Arthritis Foundation, American Lung Association, American Parkinson's Disease Association
  - The Alzheimer's Disease and Related Disorders Association, if relevant to any caregivers
  - Impairment-related organizations dealing with incontinence, loss of hearing, vision, and mobility
  - AARP, which deals with many issues facing the over-50 population
- Alternative living arrangements
  - Congregate living facility
  - Sheltered, or service-assisted housing
  - Life care community
  - Foster homes
  - Hospice
  - Nursing homes
- Financial assistance
  - Fuel assistance
  - Housing assistance
  - Miscellaneous assistance
  - Social Security Administration
  - Internal Revenue Service
- Legal assistance
- Recreation
  - Classes
  - AARP chapters/RTA units
  - Senior citizen centers
- Getting the best results when telephoning
  - Always ask the name of the person on the other end of the line
    - Makes that person feel more important
    - Makes a second call to the same agency easier if you can go back to the same person
    - Exchanging names makes the call a little more personal so one is more apt to get positive results

- Ask to speak to the supervisor to get a problem straightened out
- Local organizations or government representatives to call for assistance in solving a problem

Be sure to include any resources marked especially by host; those are resources that caregivers in the group may have a particular need to hear about.

If a caregiver in the group has had experience with a particular resource, have him or her share that experience

- Be prepared to tactfully cut off anyone who is too talkative

Caregiver may be feeling OVERWHELMED by the task of providing around-the-clock care

Caregiver may be in more than one new role, if, for example, the care recipient had taken care of all the finances, or all the household operations. Caregiver should learn all he or she can about the community resources available, including nursing homes. Knowing what the fall back resources are, should they be needed, will make the present situation easier to cope with.

Caregiver may be UNCOMFORTABLE USING COMMUNITY RESOURCES because he or she associates it with welfare

It should be stressed that the concern for the well-being of informal caregivers and their care recipients is a national, not just a local or personal, issue. Funds are being made available for services not because caregivers don't have the money, but because it is recognized that caregivers need support and assistance. Also, some of the services may be priced based on one's income. Caregivers should be encouraged to seek help to maintain their own best health and prevent burnout.

Caregiver may be RESENTFUL

It is understandable how giving up lots of personal time, vacations, social life, etc., might make one feel resentful. The caregiver may even be homesick if he or she is in the care recipient's home. Caregiver should be encouraged to let others help the care recipient to the extent that community and financial resources allow. Being resentful of the caregiving situation might get in the way of caring about and loving the care recipient as a person.

Caregiver may be BURNED OUT

The greatest need of the caregiver, according to most people who work with caregivers and the caregivers themselves, is for respite. BEFORE the caregiver becomes burned out he or she should find out about the community resources. Begin taking advantage of respite or opportunities to spend time away from the care recipient, to prevent burn out. Also, the care recipient will benefit more from the social aspects of the community services the earlier they are taken advantage of.

Care recipient may feel ISOLATED

In spite of being ill or less able to get around, to the extent possible the care recipient still needs some contact with the outside world - for diversion from his or her personal situation, to be with friends, for respite from the caregiver, for something new to talk about, for more stimulation than the TV and the same four walls provide.

Care recipient may be feeling SORRY FOR HIMSELF OR HERSELF

If care recipient does not get out much, the feeling might well be that no one is as bad off as he or she is. Exposure outside the home to persons who are worse off might lessen the tendency for self-pity and give the care recipient a chance to care about others.

Care recipient may feel DISSATISFIED with present living situation

This is most likely to happen in a situation where the parent has come to live with the child or vice versa, and life-styles don't match well. The care recipient may be truly dissatisfied, or the complaining may be a way of getting attention. Try to find out from the care recipient if there is something specific bothering him or her that might be changed. If other ideas to get the care recipient to be more accepting of the situation have not worked, taking care recipient on a tour of other accommodations available might make home look better. Caregiver should also use it as time to gather information on resources in the community.

SUMMARY FOR PRESENTATION OF MODULE #2
ON
COMMUNITY RESOURCES

GOALS

- o Discuss community and other resources
- o Have caregivers share experiences with resources
- o Help caregivers feel comfortable seeking and accepting assistance

EMOTIONS

- o Caregiver feeling
  - overwhelmed
  - uncomfortable
  - resentful
  - burned out
- o Care recipient feeling
  - isolated
  - self-pity
  - dissatisfied with living situation

GETTING ACQUAINTED WITH COMMUNITY RESOURCES (65 minutes)

(After 40 minutes take 10-minute refreshment break)

Review Community Resources booklet

Include:

- o Emergency numbers
- o General information numbers
- o Food services
- o Transportation services
- o Medical services
- o Household services
- o Support services
- o National organizations
- o Alternative living arrangements
- o Financial assistance
- o Legal assistance
- o Recreation
- o Getting the best results when telephoning

GUEST PRESENTER'S PRESENTATION OUTLINE FOR MODULE #2
ON
TIME MANAGEMENT

The GOAL of Module #2 is to:
- o Look at time management in terms of the relationship between caregiver and care recipient in addition to using time most effectively.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:
- o Caregiver feeling - overwhelmed by job to be done;
  - resentful of time caregiving takes;
  - burned out;
- o Care recipient feeling - isolated;
  - self-pity;
  - dissatisfied with living situation.

Importance of good time management (20 minutes)
- o Reduce stress
  - If ample time is available to do things, or get somewhere, caregiver will be under, and put the care recipient under, less stress
- o Create free time
  - By being a little better organized caregiver may get 15-30 minutes more a day for himself or herself
- o Preserve independence of care recipient
  - If time is well enough organized, care recipient can continue to do things for himself or herself even though the tasks take more time

Suggestions for improving time management
- o Exercise patience
  - Caregiver should have other things to keep busy with while care recipient continues to do things with little or no assistance
    - o To help preserve care recipient's independence and dignity for as long as possible
      - while care recipient is trying to make a sandwich, caregiver can use that time to open the mail, write out a grocery list
      - while care recipient is getting dressed, caregiver can get put away clean clothes, gather dirty clothes, change the bed
  - If care recipient is interruptive when caregiver is trying to complete a task
    - o Have some small tasks available for care recipient to keep busy with
      - Fold towels
      - Fold silverware into napkins for the next meal
      - Pick up twigs from the yard
    - o Have some "pretend" task to be done

      - Dough to mix, papers to cut
- Make a list
  - Helps organize thoughts about what is to be done
  - Nothing is forgotten which would later waste time if it had to be done alone
  - Tasks written down are easier to prioritize
    - Caregiver should consider what the next day will be like if a task doesn't get accomplished
    - Items with the least impact should be done last
  - Easier to group together tasks which are best done together
- Break big goals into several small ones
  - To feel accomplishment quickly rather than getting bogged down with a task never completed
  - Tackle the hardest goal first because that reduces the stress of dreading a difficult task still ahead
  - Can put short bursts of energy into a task if the end is easily in sight
    - Plan to clean only one room, not whole house
    - Plan to exercise only 15 minutes, not 1 hour
- Being organized
  - Have a small stash of cleaning supplies in every room
  - To put food away after a meal, or after shopping, collect everything to go in the refrigerator in one spot and put it all away at once
  - Collect all things to go up or downstairs in one spot by the stairs and take them all in one trip
    - Unless you want the exercise more than the time saved
  - Never go from room to room empty handed; take something with you
  - Make a list of friends you would feel comfortable asking to do one errand for you
    - Friend going to the Post Office anyway can get stamps once a week
    - Friend who picks up a medication 2 times per month can get your medications 2 times per month
    - Friend who walks daily can walk to your house and share a 10 minute cup of tea; you get the company
    - Friend who gets her hair done 1 time per week can occasionally help take care recipient in for an appointment at the same time

SUMMARY FOR PRESENTATION OF MODULE #2
ON
TIME MANAGEMENT

GOALS

- o Look at time management in terms of the relationship between caregiver and care recipient in addition to using time most effectively.

EMOTIONS

- o Caregiver feeling
  - overwhelmed
  - resentful
  - burned out
- o Care recipient feeling
  - isolated
  - self-pity
  - dissatisfied with living situation

IMPORTANCE OF GOOD TIME MANAGEMENT (20 minutes)

Goals

- o Reduce stress
- o Create free time
- o Preserve independence of care recipient

Suggestions for improving time management

- o Exercise patience with care recipient
- o Make lists
- o Break big goals into smaller ones
- o Organizational tips

GUEST PRESENTER'S PRESENTATION OUTLINE FOR MODULE #3
ON
HOME ENVIRONMENT

The GOALS of Module #3 are to:

- Provide practical tips on setting up care recipients' home and room for both safety and ease of care;
- Deal with emotional aspects of making changes in the home.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Care recipient feeling
  - insecure, frustrated or homesick in the different surroundings;
  - frustrated that she or he can't participate in household chores;
  - resentful of caregiver's good health;
  - unloved or not needed because someone else is doing his or her job;
  - anxious because some jobs around the house aren't getting done;
  - hurt, resentful, fearful when the caregiver goes out;
- Caregiver feeling
  - angry that home is no longer as clean;
  - insecure, not wanting to let go of the past;
  - guilty about having fun.

SHOWING OF FILM "The Hundred Penny Jar" and discussion (23 minutes)

- Synopsis

  Mike's mother wants to throw out the half-rotten wooden box in which Aunt Dew keeps pennies for each year of her life. But Aunt Dew protests, "When I lose my hundred penny box, I lose me," and Mike movingly defends her. The loss of independence, the struggle to maintain identity and orientation, the life review process, and the unrecognized strengths of the frail elderly are clearly illustrated. Also shown are difficulties in the caregiver's role and the caregiver's conflicting feelings about these responsibilities. Michael's interactions with Aunt Dew suggest sensitive ways of relating to the elderly.

PREPARATION OF HOME ENVIRONMENT (40 minutes)

Keeping the environment the way it is

- The sense of security from familiar surroundings is one advantage of care in the home versus care in an institution
  - Sense of security makes coping with illness easier

- If care recipient has to be moved from his or her most familiar setting, ask care recipient, or at least consider carefully, what pieces of furniture or knick-knacks might also be moved to provide sense of familiarity and security (the penny box, for example)

Care recipient may be feeling INSECURE, FRUSTRATED, HOMESICK

Being in different surroundings, with different activities going on around, often produces insecurity. Additionally, if care recipient is normally neater or less neat than the person in charge of the new surroundings, that could be frustrating.

Try to change care recipient's surroundings as little as possible so that care recipient has more emotional energies to cope with medical procedures, for example.

Changing the environment

- o Invite friend from outside caregiving situation to look at environment objectively, with no emotional attachment to how things were in past, and make suggestions as to what changes might be made

Caregiver may be feeling INSECURE

As a way of holding onto the past rather than accepting the present, caregiver may resist making changes to the surroundings, or not even be able to see what changes need to be made.

- For ease of care
  - o Move bed from upstairs to main floor room, even though room is not a "bedroom"
  - o Put up memory and orientation aids to help care recipient remember important things
    - On a blackboard write the day of the week, date of the month, year, season, what the weather is like outside, who is coming to visit that day
    - Put up signs showing which way to the bathroom, the care recipient's bedroom, the kitchen
    - Use pictures for directions rather than words (like a picture of a toilet on the bathroom door)

  - Add extension to toilet seat
  - Add downward extensions to light switches so they can be reached from a wheelchair
  - Have family members exchange bedrooms so care recipient will be closer to the bathroom
  - Add height to bed, chairs, tables if it will make it easier for caregiver or care recipient
    - Stack furniture on wood, books or bricks, making sure that leg of furniture will not slip off
- For safety (distribute "Home Safety Checklist for Older Consumers")
  - Prepare as much of house for safety as possible, not just care recipient's room, so she or he will not feel confined to being comfortable and safe in just one room
  - Encourage caregivers to check their homes against this list and make recommended safety changes
    - In addition, ask caregivers to add to the "Home Safety Checklist":
      - Make sure oven door is closed to prevent running a leg into the corner of the door (kitchen section of "Checklist")
      - Glass doors need decorative stickers at each resident's eye level, or sheer curtains in front of them, to prevent someone from walking into the doors (living room section of "Checklist")
      - Pad any sharp table corners to prevent injury should care recipient bump or fall onto them (living room section)
      - Bedspreads should be removed or seamed down the outside corners to prevent tripping on excess spread at the bed corners, and to prevent someone running a leg into any sharp bed frame corner hidden by the spread (bedroom section of "Checklist")
      - Make sure dresser drawers are left closed (bedroom section of "Checklist")
      - Uneven, high-trafficked outdoor walking surfaces should be evened out with appropriate materials to prevent tripping (last page of "Checklist")
    - Caregivers of dementia patients need to be aware of their tendency to let water run
      - Danger of sink overflowing and slipping on wet floor
- For more pleasant surroundings
  - Make room where care recipient spends most of his or her time clutter-free, but not "sterile" for a more peaceful environment

    - Less clutter will help a care recipient with memory impairment because the brain will not have so many items to choose between
  - o Have comfortable sitting area to encourage visitors
  - o Fill room with as much fresh air and sunshine as possible
  - o Have cheerful things around, like stuffed animals, plants, fresh flowers, a pet
- If possible, consult with care recipient on changes that are intended to "benefit" him or her, in case they won't
  - o For example, before you install support bars, find out how your male care recipient stands at the toilet; maybe he stands at the side, not in front of the toilet, so he can rest up against the bathroom counter

Cleanliness

o Routine cleaning
- Your care recipient may be less concerned about how clean the surroundings are as other things become more important
- Dirt and dust need to be kept at a minimum for the sake of health and sanitation
- The commotion of a vacuum cleaner, or smell of a dusting spray may unsettle the care recipient
  - o If the process of cleaning upsets care recipient, arrange to do it/have it done while care recipient is out of the room, or house, or is distracted by something or someone

Care recipient may be feeling RESENTFUL

In spite of the fact that someone else is helping the care recipient by doing the cooking and cleaning, the care recipient may resent the fact that the caregiver is healthy enough to do these things. If the care recipient had to be moved out of his or her own home because of not being able to cook and clean, the care recipient may be resentful of having to give up a home just because he or she is now unable to cook and clean.

Care recipient may be feeling UNLOVED OR UNNEEDED

If someone else has been brought in to do the job you had always done, you would feel unneeded also.

Find some tasks which care recipient can do to continue feeling useful - folding towels (they don't have to be perfect), wrapping silverware in a napkin for dinner, putting ice in glasses for water, watering the plants, etc.

Care recipient may be feeling ANXIOUS

Especially for a care recipient who does not get out of the house very much, the fact that curtains don't get washed, lawn and flower beds don't get tended, windows don't get washed, etc., may produce unnecessary anxiety that will interfere with coping with other more important problems.

Look into a chore service or see if a church or synagogue might have some way to get those tasks done to reduce the care recipient's stress level.

Care recipient may be feeling FRUSTRATED

If the care recipient used to pride him or herself on being a good cook, and keeping a clean house, not being able to do those tasks now may be frustrating. The person who is doing those tasks for the care recipient is also probably not doing them the exact same way, which may be frustrating for the care recipient.

Caregiver may be feeling ANGRY

A very clean house was one thing the caregiver has always been proud of. Now the care recipient's reaction to the cleaning noises and smells keeps the caregiver from cleaning the way it used to be done.

Caregiver needs to decide if there is room for compromise. Could the vacuuming be done every other day, instead of every day, with no ill effects? Could someone come in and clean while caregiver takes care recipient to the doctor? The caregiver insisting on not changing a cleaning routine in spite of friction caused with care recipient may be a sign of caregiver unwilling to let go of the past and deal with the present. In spite of the fact that cleaning is something caregiver can do, it is also something that a stranger could do sufficiently well, with the end result that a source of contention might be dissolved and the caregiver would have a little extra time for something a stranger can't do.

o Special considerations
  - Caregiver should be careful to wash hands thoroughly under running water after handling bedpan, portable commode, pants shields, tissues, etc., to prevent spread of germs and bacteria
  - To make cleaning up vomit easier, keep a plastic broom and dustpan handy; implements can easily be rinsed afterwards

View from the outside world

o Preventing isolation of caregiver and care recipient
  - In spite of, and because of, caregiving situation, visitors should be encouraged

- Since caregiver and care recipient cannot get out as much themselves
- Because it is important to remember that the world is still going on outside the home of the caregiver
- Because both the caregiver and the care recipient need the variety, stimulation and attention of visitors
- Because both the caregiver and the care recipient still need to laugh and have fun

Caregiver may be feeling GUILTY

It may feel inappropriate to have company, or laugh and have fun while someone is ill in the house. Or caregiver may feel guilty about having a good time when care recipient isn't feeling well enough to join in. For a variety of reasons the caregiver needs to maintain friendships and take advantage of opportunities to do fun things - because the caregiver has a life to live too, apart from being a caregiver, and because the caregiver desperately needs the respite that friends, outings, and a change of scenery or pace offer. The care recipient may even get some vicarious enjoyment out of it.

- Preparing home for visitors
  - Odors in the home
    - A declining sense of smell, part of the normal aging process, might prevent even the caregiver from being aware of odors that visitors might find unpleasant
      - Preventing unpleasant odors
        - Empty bedpans and portable commodes immediately after use and clean with fresh smelling cleanser
        - Keep bedclothes fresh and clean including blankets which can be tossed in a dryer or hung on a line to air out
        - Empty wastebaskets and garbage frequently to a larger outdoor container
        - Wash dirty dishes immediately or soak them in soapy water
        - Keep cat litter box clean and canned pet food covered
      - Creating pleasant odors
        - Use lotion, cologne or perfume on care recipients after they have bathed
        - Let fresh air in to circulate
        - Put a bouquet of aromatic flowers in one or more rooms

- Bake something chocolate before guests arrive
- Put some water to simmer on the stove with orange peel, cloves, cinnamon, and nutmeg in it, being careful the water does not boil away
- Find a room freshener you like and use it sparingly
- Add some drops of peppermint extract to the water in the humidifier

- Appearance of the home
    - Don't worry about what friends or strangers will think if they see signs on the walls, an extension on the toilet seat, a bed in the dining room
        - Friends will understand
        - It won't matter what strangers think
        - Most people will be impressed with, and admire, how you are coping with a difficult situation
- Planning for respite caregiver

Care recipient may be feeling HURT, RESENTFUL, FEARFUL

When the caregiver is ready to go out, or on a trip, the care recipient may complain about being left behind, or comment on the fact that the caregiver is going out "again". The care recipient also may have an attack of some kind, real or imagined or faked, to coincide with the caregiver's departure. It may be resentment that the care recipient is not well enough to go too; it may also be fear that if something happens to the caregiver while away from home, there will be no one to take care of the care recipient.

While the caregiver needs to get out of the house as one way of relieving stress and keeping a perspective on the situation, the departure may in fact create stress for the care recipient. Caregiver should prepare the care recipient by reassuring him or her as to the plans for respite care in the caregiver's absence. Caregiver should not let care recipient be manipulative and prevent caregiver from taking a much needed break.

- Caregiver's first choice should be for care recipient to be out of the home for respite
    - Preparing for a stranger to come into caregiver's home could be exhausting all by itself
    - No need to worry about valuables in the home with a stranger there
    - Caregiver may want to use respite time at home, not on a "vacation"

Possibilities for help with home adaptations

- Religious, fraternal or youth organizations
  - Often seek opportunities to help people
  - Have a variety of skills among the group members
  - Will sometimes have funds with which to do projects
- Be specific in what your needs are
- If you can't pay for materials or labor you might offer a small donation to the group or have a home-baked treat for the workers

SUMMARY FOR PRESENTATION OF MODULE #3
ON
HOME ENVIRONMENT

GOALS

- o Prepare home for safety and ease
- o Emotions of making changes

EMOTIONS

- o Care recipient feeling
  - insecure, frustrated, homesick
  - unloved or unneeded
  - anxious
  - hurt, resentful, fearful
- o Caregiver feeling
  - angry
  - insecure, hanging on to the past
  - guilty

SHARING AND REFRESHMENTS (12 minutes)

FILM (18 minutes) AND DISCUSSION (5 minutes)

PREPARATION OF HOME ENVIRONMENT (40 minutes)

Keeping environment the way it is

- o Security in familiarity

Changing environment

- o Get objective opinion
- o For ease of care
- o Safety checklist and additions
- o For cheerfulness

Consult with care recipient on changes

Cleanliness

- o Routine cleaning
- o Special considerations

Preparing for visitors - view from the outside world

- o Preventing isolation
- o Preventing unpleasant odors
- o Creating pleasant odors
- o Appearance of home

Planning for respite

Possibilities for help with home adaptation

GUEST PRESENTER'S PRESENTATION OUTLINE FOR MODULE #3
ON
EXERCISE

The GOALS of Module #3 are to:

- o Stress the importance of exercise for both caregiver and care recipient;
- o Provide examples of exercises.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- o Care recipient feeling
  - frustrated that she or he can't participate in household chores;
  - resentful of caregiver's good health;
  - hurt, resentful, fearful when the caregiver goes out;
- o Caregiver feeling
  - guilty about having fun.

EXERCISE (45 minutes) demonstration and practice

Lead caregivers in 5-10 minutes of simple exercises using several examples from AARP's turquoise "Additional Resources" booklet if it is being used .

- o Functions as a relaxing program break
- o Demonstrates something relaxing and healthful to do at home also

Importance of exercise for caregiver and care recipient

- o Physical aspects of exercise for everyone
  - Long periods of sitting or lying down speeds deterioration of the body, especially the muscular and cardiopulmonary systems
  - Using muscles prevents atrophy (a condition where muscles decrease in size and strength and cannot be used) and increases muscle strength and mass
  - Movement increases circulation, which in turn increases the supply of oxygen and removal of waste in all parts of the body
  - Exercise will help retain bone mass and help prevent breaks and fractures
- o Exercise for the care recipient
  - Care recipient may be afraid that exercising will harm rather than help him or her
    - o Caregiver may know otherwise but be unable to convince care recipient
    - o Ask doctor to discuss exercise specifically next time since care recipient will often do things for others, especially if "the doctor said", when she or he won't for family

  - Care recipient with dementia may appear listless and uncaring about the surroundings
    - Although the inactivity may be easier for the caregiver, as much activity as possible is important for care recipient's overall well-being
      - Enlist help of others to keep care recipient active
  - Doing everything possible to keep muscles, heart, and lungs in the best possible shape will give care recipient a positive edge in fighting disease processes
  - Maintaining circulation and muscle strength will help preserve care recipient's independence for the longest possible time
  - Better blood circulation will decrease the chance for pressure sores (topic in next module)
- Exercise for the caregiver
  - Caregiver needs to stay healthy so there aren't two care recipients instead of one
  - Good muscle tone will help prevent injuries when doing things for the care recipient
- Mental health aspects of exercise
  - Exercise usually works well to reduce stress and/or depression
    - To regain composure from lack of patience or an argument
    - To let your brain subconsciously work on problems when a conscious effort has not brought solutions
    - Tuning in to the physical feelings of exercise will allow a temporary break from being tuned in only to the stresses of caregiving

Exercising properly

- Check with a doctor before beginning any exercises for weight loss or cardiovascular fitness
- Exercises do not need to hurt to be helpful
- Start with a short period of exercising and gradually increase

Fitting in exercise

- Increase care recipient's activity without setting time aside solely for exercise
  - If care recipient takes a bath, help him or her do range-of-motion exercises while in the bathtub (see exercise examples in AARP's turquoise Additional Resources booklet)
  - If care recipient can walk without pain, with or without aid, build in slightly longer rather than shorter walks
    - Allow 15 extra minutes when going someplace
    - Park car an extra block away rather than as close to the destination as possible
  - Make a list of things care recipient might do for you that will be helpful and can be done in his or her own good time, even if it would be easier for you to do yourself
    - Walk out to get the mail and/or newspaper

- Bring in firewood (one piece at a time is fine)
- Take dirty laundry to the washing machine (making five trips is fine)
- Bring back the empty garbage can
- Borrow a cup of sugar from the neighbor
- Allow care recipient to do everything possible for himself or herself
  - Has added benefit of preserving care recipient's independence and dignity to the extent possible
- Plan specific exercise time
  - Any increase in activity/exercise will be beneficial
  - Set small goals for increased exercise to experience the satisfaction of reaching the goal
    - For dementia care recipients, try a chart with gummed stars; when he or she reaches a goal, plan a special reward
  - View planned exercise time not as wasting or using up precious time but as important for both care recipient and caregiver as three balanced meals
  - Enrolling in an exercise class will offer the discipline of a regular exercise time plus the added benefits of being with other people
  - Exercises that can be done with other family members:
    - Swimming
      - Water will support weight of body and provides a good place to do range-of-motion and stretching exercises, in addition to swimming
      - Beneficial even if flotation device is used but care recipient still has opportunity to move arms and legs
      - May want to enroll in therapeutic swimming class
      - Side benefit of being able to bathe at same time by having soap handy for shower before entering or after leaving the pool
      - Have a large bath or beach towel, or terry cloth robe, handy for the time care recipient is out of the water
    - Walking
      - Walk around the block, yard, or living room even with an aid
      - In inclement weather, walk in a covered mall
    - Biking
      - For someone who has trouble walking because of poor balance, tendency to stumble or pain while walking, riding on a stationary bike may still be possible
        - Make sure the bike is situated so care recipient is not in danger of falling off
      - A tandem bike for two people, or a three wheeled bike might be considered
    - Wheelchair exercise

- Propelling himself or herself will be exercise for the care recipient who uses hands and arms on the wheels, or feet on the ground
- Many stretching and strengthening exercises can be done from the sitting position

SUMMARY FOR PRESENTATION OF MODULE #3
ON
EXERCISE

GOALS
- o Importance for both caregiver and care recipient
- o Provide examples

EMOTIONS
- o Care recipient feeling - frustrated
  - resentful
  - hurt, fearful
- o Caregiver feeling - guilty

EXERCISE (45 minutes) demonstration and practice

Lead group in 5-10 minutes of simple exercises for break

Importance of exercise for caregiver and care recipient
- o Physical aspects for everyone
- o Exercise for care recipient
  - Care recipient may be afraid
  - Benefits
- o Exercise for caregiver
- o Mental health aspects

Exercising properly
- o Check with doctor
- o Don't create pain
- o Start with short period
- o Range of motion, stretching, strengthening

Fitting in exercise
- o Increase activity
- o Plan specific time

GUEST PRESENTER'S OUTLINE FOR MODULE #4
ON
MOBILITY

The GOALS of Module #4 are to:

- o Make mobility for the caregiver and care recipient safer and easier;
- o Stress the need for the caregiver to take care of himself or herself both physically and emotionally.

EMOTIONS to listen for during conversation, reiterate for emphasis,or mention if no one does:

- o Caregiver feeling
  - angry about the illness;
  - frustrated about being tied down;
  - a need to practice denial;
  - too proud to seek help;
- o Care recipient feeling
  - angry about dependency;
  - afraid to try something new;
  - insecure about home care.

MOBILITY (45 minutes) demonstration and practice

Importance of preserving or increasing mobility for care recipient

- o Ask caregivers to name some advantages
  - Their naming advantages will fix in their minds that this is a positive goal of utmost importance

Caregiver may be feeling ANGRY

A disease or the aging process is slowly debilitating a loved one and that's worth being angry about. Or the caregiver may be angry AT the care recipient - for getting sick, for ruining present and future plans.

After feeling the anger, caregiver needs to move on. Take one day at a time; look for the bright spots and things to be grateful for; keep a sense of humor. Reevaluate life with the care recipient frequently so that each day the care recipient can be accepted for who he or she is, and what he or she is capable of doing, that day alone, not compared to the past.

Caregiver may be feeling FRUSTRATED about not being able to take the care recipient out of the house

If the idea of taking the care recipient out of the house seems overwhelming, make a list of all the things about that idea that prevent you from doing it - - can't get the wheelchair out of the house, care recipient needs a nap every hour, care recipient takes medication that needs refrigeration, etc. Then one by one see if there are ways to take care of each of those obstacles - ask a civic or religious group to build you a wheelchair ramp; plan a stop at a park in the middle of an outing so care recipient can take a nap in the car; take a cooler along with ice packed around the medication; or cash in offers of help from others to get you both out of the house. The need for both caregiver and care recipient to get out is great; don't let potential obstacles stop you.

Caregiver may be practicing DENIAL

If the caregiver convinces himself or herself that the care recipient is fine, then he or she doesn't have to worry about the care recipient. Maybe the care recipient could use a little help, or some support from beyond the caregiver such as an adult day care center could provide. People of all ages need the companionship of others their own age. A day care center, or senior center, can provide the care recipient with love and attention the caregiver may be too exhausted to give. The center doesn't know the care recipient of the past so expectations are only of what the person can do that day. The center can be fun for the care recipient, which is appropriate, just as the caregiver deserves and needs fun, and this respite from the caregiving situation.

- Address these points:
  - Preventing isolation, for both care recipient and caregiver, by making it possible for care recipient to be about or out of the house, even if just to sit outside
  - Preserving independence, by enabling the care recipient to continue to do things for himself or herself
  - Decreasing the physical and emotional stress on the caregiver by the care recipient doing some things for himself or herself
  - Adding to the better health of the care recipient by exercising more muscles, increasing circulation with every movement

Overcoming resistance to using aids for mobility

- Care recipient may be afraid of trying something new

Care recipient may be feeling AFRAID to try mobility aids

The care recipient may have a fear of falling, or that his or her muscle strength isn't great enough to do more than sit or lie around. Caregiver can help get over that obstacle by helping care recipient do some regular exercises in preparation for using an aid, and then by using the aid in gradually increasing amounts of time. Don't start off with a walk around the block in a walker.

  - Allow care recipient time to get used to the presence of the mobility aid
  - Assist in attempt to try aid out to ensure feeling of security and safety for care recipient
- Care recipient may be afraid that using aid will make him or her appear handicapped

> Care recipient may be feeling ANGRY that he or she can't be independent. Life has changed and care recipient seems to have little control. As a way of hanging on to a shred of independence, care recipient may balk at the idea of using a wheelchair or walker because of the negative connotation of being handicapped, when care recipient is trying to hang on to a more normal past.

- o Give examples of simple ways independence is gained by using an aid
  - If care recipient is mobile, he or she can spend some time at an adult day care center away from caregiver, making friends, participating in activities
  - If care recipient will use a wheelchair, she or he can go to grocery store
    - o Use wheelchair as "grocery cart" with one bag on care recipient's lap for light items and another on the back of the chair
    - o Filled bags can be left with a check-out clerk until the shopping is done
  - ASK CAREGIVERS TO OFFER OTHER EXAMPLES
- o Try to help care recipient see wheelchair or walker as an aid to walking like wearing glasses is an aid to sight

Variety of aids available

- o Factors to consider in choice
  - What the most difficult situations are that you encounter in helping care recipient get around
  - Whether care recipient will propel self or need help
  - The physical strength and capacity of care recipient
  - What kind of ground surface will most often need to be covered
  - How wide doorways and maneuvering spaces in bathrooms are
  - If there are stairs to navigate
  - How easy the aid will be to transport in a car or on public transportation
  - Which aids qualify as Durable Medical Equipment (DME) paid for by Medicare (check with Social Security office)
  - In how many situations will the aid be more of a help than a hassle, taking the needs of both the care recipient and the caregiver into account
- o Wheelchairs
  - Come in four sizes
  - Are made with a large number of variations to accommodate almost any need such as:
    - o Whether self controls for chair are all on one side or on both (important for stroke victim, for example)
    - o Whether to have foot rests, or none so care

recipient can propel self by foot power
  - Removable foot rests make transfers in and out of the chair easier and safer
- Whether arm swings away for sliding out of chair
- Whether chair is rearwheel or frontwheel drive
- Whether chair is lightweight and more portable or heavy and sturdier

- Can usually be tried out for suitability from a medical supply house or a hospital before any commitment must be made to buy/rent a particular one
- May be up to 80 per cent paid for by Medicare
- Can improvise by putting casters on regular chair or using office chair that has casters on it
  - Narrower for narrow passages (Or you can install special door hinges or remove door molding to widen passage for regular wheelchair)
  - May be cheaper than wheelchair
  - Disadvantages
    - Harder to control; make sure care recipient can stop chair
    - Less comfortable for long periods of time

- Staircase elevators
  - Helpful if care recipient can walk, sit down, and stand up, but not climb stairs
  - Can run manually or by electricity
  - Some models can go across landings, around corners and curved stairs
  - Can be rented
- Walkers
  - Come with or without wheels
    - Walkers with wheels don't roll well over carpet
- Canes
  - Options
    - Strap to go around wrist
    - Special attachment to hold it to furniture when not in use
    - Seat attached
    - Made from a variety of materials
    - Four-pronged base for additional stability

Safe transfers (Note: demonstrate these techniques while going over outline)

- Caregiver safety
  - Know your limitations
  - Seek help from a physical therapist or visiting nurse for the best way to move care recipient
  - Learn correct physical placement to withstand stress of moving someone or some object

Care recipient may be feeling INSECURE

In the hospital care recipient probably had the feeling that all the doctors and nurses knew what they were doing, and would know what to do in an emergency. Even if the caregiver knows what to do normally and in an emergency, the care recipient may not share that confidence yet. There are several ways this may become apparent, including the care recipient asking to be put in a nursing home, or the hospital, or asking to have a nurse brought in etc.

Caregiver may need to prove to the care recipient that she or he is capable. Share with the care recipient some of the things being learned in this program. The caregiver should ask questions of some professional about anything that is not perfectly clear. There are no stupid questions in caregiving.

        - Place feet apart in wide stance; bend at knees, not at hips, to reach low or lift people or objects; to turn, always move feet and torso rather than leaving feet in place and twisting torso
        - When trying to help care recipient up out of a bed, chair or car, caregiver should not let care recipient's weight be supported only by caregiver's body
            - Hold on to care recipient with one hand, something firm with the other to pull against (heavy piece of furniture, a bar on the wall, a door jam - anything that will not move)
            - Hold on to care recipient with both hands but brace foot against something very solid
        - Place a wide belt around care recipient's waist to provide a secure way to hold him or her

- Logistics of transfers
    - Use aids
        - Transfer board
            - Secure board between two immobilized places to sit so care recipient can slide from one to the other
        - Wheelchair with arm that swings out of the way
        - Hoists
            - Can be portable or fixed to the ceiling of the room(s) where most needed
            - Can lift care recipient out of bed, onto toilet, into bathtub, etc.
        - Catapult devices
            - Chair which lifts care recipient from sitting to standing position
                - An example of Durable Medical Equipment, 80 per cent of the purchase cost of which may be paid for by Medicare (more

on this in module #5) for persons with severe arthritis of the hip or knee, or a neuromuscular disease

- Portable catapult seat
- Getting care recipient out of bed
  - Have care recipient lie on side facing you
  - Move legs over the edge of the bed
  - Sit care recipient up in bed
    - Prop with pillows if necessary
  - Help care recipient to stand or slide on a transfer board
- Helping care recipient into wheelchair or walker
  - Make sure the chair or walker will not move as care recipient begins to place weight on it
    - Wheels in locked position
    - Wedge against a stable object
  - Caregiver should use one hand to help steady and lower the care recipient while supporting himself or herself on another piece of furniture
- Helping care recipient into and out of bathtub
  - When this task first becomes difficult, get some sort of seat in the bathtub so care recipient does not have to be lowered in and out
  - When care recipient is standing at the edge of the tub, facing away from the tub, caregiver can help lower care recipient onto the seat by bracing knees against the tub and leaning out as a counterbalance to weight of care recipient
  - Then from a kneeling or squat position, caregiver can help lift care recipient's legs into the tub and turn the care recipient a quarter turn
  - To get care recipient up, reverse the process
- Helping care recipient into car
  - Help lower care recipient to sit facing out on seat with one hand of caregiver on care recipient and the other on some portion of the car
  - Caregiver should kneel or squat then to help turn legs of care recipient into car
- Helping care recipient out of car
  - Make sure if there is any slope where car is parked that the passenger side of the door is on the down side
    - Gravity will help
      - Keep door open
      - Help care recipient get out of the car
  - Caregiver can brace foot against car to help care recipient out

If care recipient falls

- AVOID PANIC
- The safest place for a care recipient is on the floor because she or he can't go any further
- If care recipient falls in confined space such as the bathroom
  - Don't try to get care recipient up

        - The danger of further injury to the care recipient, or injury to the caregiver is too great
            - Getting care recipient part way up and having him or her fall again against tub, toilet, or basin
            - Caregiver straining a muscle from trying to lift from an awkward position
    - Move care recipient to a place where getting him or her up will be safer for everyone
        - Roll care recipient onto a towel or sheet
        - Drag care recipient out of the confined area to a place where caregiver can get some support
            - From caregiver bracing self against a wall
            - From hanging on to furniture, or having furniture on which care recipient can help pull him or herself up
            - Where two people have enough room to help the care recipient up
            - Where caregiver can prop care recipient up on pillows so the care recipient is not being brought up from a lying position
- If care recipient must stay on the floor
    - Because caregiver cannot get him/her up without help
    - Because caregiver is quite sure there are broken bones
        - Make care recipient comfortable on the floor with pillows and blankets
        - Wait for someone to help

Caregiver may be feeling too PROUD or stubborn to ask for help, or too impatient to wait for it.

Caregiver should not try to be a martyr, or a hero, moving and lifting the care recipient in spite of caregiver's own limitations. The idea that the caregiver is not doing his or her job if someone has to help is part of an unwarranted guilt trip that caregivers often put on themselves, or that care recipients put on them.

Transporting a wheelchair

- Back of car
    - Carrier holds chair on backend like bikes are often carried, but caregiver must be able to lift chair onto carrier
- Trunk of car
    - Difficulties in getting chair in and out of trunk
        - Portions of chair getting caught on edges of trunk
        - Weight of chair
        - Technique to overcome both

- Place a large piece of folded, sturdy cardboard (cut from side of an appliance packing box, for example) between car and chair
- Rest one end of cardboard on ground, top edge should come above open trunk space
- Place folded chair beside cardboard
- From kneeling or squatting position, push/slide chair up the cardboard until chair and cardboard can be tipped into trunk space
- To remove chair, reverse process

If care recipient is too mobile

- Make sure care recipient wears an ID tag
    - Care recipient's name and a phone number, but no address
    - Alert neighbors, police in the area if care recipient is a potential wanderer
    - Make sure temporary contact information is on ID tag if care recipient is on a trip
- Restricting the wandering care recipient
    - By distraction
        - If care recipient's state of agitation is acted out by wandering, take the care recipient for a drive or a walk to calm him or her down
        - Engage the care recipient in some activity around the house, like opening mail, folding newspapers for fireplace, etc.
    - By physical means
        - Take away the coat or hat the care recipient always insists on wearing before going out the door
        - Put "childproof" doorknob cover on doors
        - Last resort due to danger of not being able to get out easily in an emergency
            - Never use if anyone in house smokes
            - Lock the doors and place key in out of the way place that is both memorable and easily accessible
                - Consider putting door locks in a new place, like at top or bottom of door
    - By sleep cycle
        - If care recipient does not sleep at night and wanders, try keeping him or her up later into the evening so she or he will sleep through the night
- Restricting driving if care recipient is unsafe on the road
    - Persuade your care recipient by focusing not on why he or she is an unsafe driver, but rather on how awful it would be if care recipient hit a child while driving

SUMMARY FOR PRESENTATION OF MODULE #4
ON
MOBILITY

GOALS

- Make mobility safer and easier
- Stress the need for the caregiver to take care of himself or herself

EMOTIONS

- Caregiver feeling
  - angry
  - frustrated
  - denial
  - too proud
- Care recipient feeling
  - angry
  - afraid
  - insecure

WELCOME AND SHARING (10 minutes)

MOBILITY (45 minutes) demonstration and practice

Importance of preserving or increasing care recipient's mobility

- Preventing isolation
- Preserving independence
- Decreasing physical and emotional stress
- Increasing circulation

Overcoming resistance to using mobility aids

- Care recipient afraid
- Care recipient not wanting to appear handicapped

Variety of aids available

- Factors to consider when choosing an aid
- Wheelchairs
- Staircase elevators
- Walkers
- Canes

Safe transfers

- Caregiver safety
  - Learn correct body movement
- Logistics of transfers
  - Use of aids
  - Helping care recipient
    - out of bed
    - into wheelchair or walker
    - into and out of bathtub
    - into and out of car

If care recipient falls

- Avoid panic
- Safest place is on the floor

- If fall is in the bathroom
- What to do if care recipient must stay on the floor

Transporting a wheelchair
- Back of car
- Trunk of car

If care recipient is too mobile
- Care recipient must wear an ID tag
- Restricting the wandering care recipient
  - By distraction
  - By physical means
  - By sleep cycle
- Restricting care recipient who is unsafe on the road

REFRESHMENT BREAK (10 minutes)

GUEST PRESENTER'S OUTLINE FOR MODULE #4
ON
BED CARE

The GOALS of Module #4 are to:

- Make mobility for the caregiver and care recipient safer and easier;
- Stress the need for the caregiver to take care of himself or herself both physically and emotionally.

EMOTIONS to listen for during conversation, reiterate for emphasis,or mention if no one does:

- Caregiver feeling
  - angry about the illness;
  - frustrated about being tied down;
  - a need to practice denial;
  - too proud to seek help;
- Care recipient feeling
  - angry about dependency;
  - afraid to try something new;
  - insecure about home care.

TENDING THE CARE RECIPIENT'S BED (45 minutes) demonstration and practice

(NOTE: In the unlikely instance that no caregivers in the class have a care recipient who is bed bound, it may be wise to cover this material for their future reference.)

Importance of timely movement of immobile, or partially immobile, care recipient

- Any movement increases blood circulation
  - The slower the blood circulation, the greater the chance that even small amounts of pressure for extended periods of time can cause pressure sores (decubitus ulcers and bedsores)
    - Caused by blocking the supply of blood, and therefore oxygen and nutrients, to skin cells; the cells dead from lack of blood are the visible pressure sores
    - Once sores appear they are difficult to get rid of
    - Preventing pressure sores
      - Bottom bed covers should be pulled tight and kept wrinkle free to prevent sheet wrinkles from causing sores
      - Care recipient should change, or have changed, his or her position every two hours
        - Position should even be changed through the night, unless it is a question of moving the care recipient versus the caregiver getting a desperately needed night of sleep

- Demonstrate a pull sheet, a flat sheet folded into quarters and put under the torso of the care recipient with long ends over side of bed
  - To turn care recipient from one side to the other
    - Starting on the side of the bed care recipient is facing, toss one end of pull sheet over him or her to other side of bed; go to other side of bed and gently continue to pull the top part of the pull sheet until care recipient is turned over
- Aids that can be used to decrease the number of pressure points which cause sores
  - Eggcrate mattress for the bed
  - Heelpads for the heels
  - Inflatable "doughnut" to sit on
  - Sheepskins for the bed or wheelchair
  - Small cushions between knees and ankles for care recipient lying on his or her side
- Sitting up occasionally will help move the oxygen in and out of the care recipient's lungs and is preferable to lying down all the time
  - Using pull sheet to help care recipient sit up
    - With one person on each side, roll up pull sheet close to body of care recipient and pull forward together
      - Good technique especially if hands and arms on back of care recipient will cause pain
      - Allows caregivers to maintain better posture
  - Care recipient should be prevented from sliding down from the sitting position; when the body slides down but the skin clings to the bed covers, the wrinkling of the skin could cause pressure sores
    - Once care recipient is sitting, prepare a foot stop for the sitting position, such as a sturdy box or a stool on its side wedged between the foot of the bed and the care recipient's feet
    - Have a way care recipient can pull himself or herself back up, such as a trapeze or rolled sheet around the headboard of the bed

Changing linens of immobile, or partially immobile, care recipient

- Height of bed
  - Factors to consider in height of bed
    - Ease in making bed
    - Ease for getting in and out of bed
    - Other activities at the bed, such as exercise, feeding, etc.
  - Hospital beds crank up or down

  - Regular bed can be raised by purchased supports or by wood blocks
    - Make sure bed legs will not slip off supports, or supports will not be kicked out from under bed
- Caregiver should protect his or her own health
  - If bed is double sized, or care recipient is too heavy to move easily, caregiver should seek help from a family member, neighbor, or home health aide in changing bed
  - Bed-changing technique
    - Have a blanket roll or 2-3 small pillows, clean bedding, any pads and new pull sheet handy
    - Roll care recipient to one side of bed with old pull sheet
    - Prop him/her there with a blanket roll or small pillows the length of care recipient's back, or by tucking pull sheet in
    - On open side of bed, remove old linens, rolling from the edge toward the center, and use old linens to replace blanket roll/pillows in propping care recipient to one side
    - Put pads, new linens, and pull sheet on the bare side of the bed and make smooth; roll second half of new linens that will go on the side care recipient is presently lying on down toward the center of the bed and place by roll of old linens
    - Using old pull sheet, pull care recipient over the roll of old and new linens to the clean side of the bed
    - Prop care recipient there with blanket roll or small pillows
    - Grab roll of old linens and completely remove
    - Grab roll of new linens and pull tightly over remainder of the bed

Supports for maximum comfort in bed

- On back
  - Put a pillow under the knees
  - Put a board in bed to rest feet against
    - Board should come just above care recipient's toes to keep weight of bed clothes off the care recipient's feet but allow the covers to rest on the thighs and legs
    - Good for care recipient to push against to move self back up in bed
- On side
  - Put pillows or rolled blankets at the back
    - Place at end of pull sheet and roll pillows or blanket roll under until you get to the care recipient's body to prevent it from unrolling on its own
    - Provides sense of security
    - Keeps care recipient from rolling onto his or her back
  - Put a pillow at the chest for the free arm to rest on

- Put a pillow at the knees so top leg can be bent slightly and lie out on the pillow (this also helps prevent pressure sores between the knees)

SUMMARY FOR PRESENTATION OF MODULE #4
ON
BED CARE

GOALS
- Make mobility safer and easier
- Stress the need for the caregiver to take care of himself or herself

EMOTIONS
- Caregiver feeling
  - angry
  - frustrated
  - denial
  - too proud
- Care recipient feeling
  - angry
  - afraid
  - insecure

WELCOME AND SHARING (10 minutes)

MOBILITY (45 minutes) demonstration and practice

REFRESHMENT BREAK (10 minutes)

BED CARE (45 minutes)

Importance of timely movement of care recipient
- Increasing blood circulation
- Preventing pressure sores
  - Demonstrate pull sheet
  - Aids to prevent pressure sores
- Sitting up
  - Pull sheet maneuvers
  - Ways to keep from sliding down in bed

Changing linens
- Change height of bed as needed
- Protect caregiver's health
  - Bed-changing technique

Supports for maximum comfort in bed
- On back
- On side

GUEST PRESENTER'S PRESENTATION OUTLINE FOR MODULE #5
ON
FINANCES

The GOALS of Module #5 are to:

- Provide caregiver with the tools to handle finances and financial problems more effectively;
- Suggest financial options that may not have occurred to the caregiver.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does:

- Care recipient feeling - hurt, angry, resentful, scared or selfish over issue of someone else handling finances;
- Caregiver feeling - overwhelmed at needing to learn about finances.

GETTING A GRIP ON FINANCES (80 minutes with a 10-minute refreshment break after 40 minutes)

Who's in charge

- When care recipient can no longer handle the finances, don't put off making a necessary change in the management of the finances to spare his or her feelings
  - Have care recipient assign someone durable power of attorney in case he or she becomes incompetent (do only when absolutely necessary) NOTE: the next module will cover the legal options for designating someone else to make decisions
  - Continue to involve the care recipient in the decision making for as long as possible
  - If care recipient refuses to give up control of finances
    - Use checkbook with automatic carbon copy of each check written so check register will be maintained
    - Enlist the support and patience of persons/organizations to whom checks may be written incorrectly
    - Handle financial matters while care recipient is asleep or out of the house if need be

Care recipient may be feeling HURT, ANGRY, RESENTFUL, SCARED, SELFISH
If care recipient has always handled the finances but is no longer able to, he or she may not be comfortable having someone else just take over. It may feel to the care recipient that the family is acting like he or she is already dead, that careful financial plans of the past are about to be undone, that no one else can do it as well as the care recipient did.

- o Caregiver is newly in charge of finances and needs help
  - Ask for help from family or friends

Caregiver may be feeling OVERWHELMED at needing to take over the finances

Stepping into financial management while under the stress of caregiving can be awesome, especially for one not used to handling finances. Remind the caregiver that most things are easier if done in small steps. So will be the task of taking over the finances.

  - o Even with help, caregiver should stay involved as much as possible
    - Making all final decisions
    - Signing all checks
    - The more the caregiver is involved
      - o The less dependent caregiver is on the assisting family member (son, daughter, etc.)
      - o The better the precedent for being part of decisions in the event the caregiver wants to overrule a decision of person who is assisting
      - o The more able the caregiver will be to act on his or her own if the assisting family member is not around at a crucial moment to help with a decision
  - At a bank where caregiver has an account, ask for someone to simply help caregiver start the organization process (should be no charge)

Expenses

- o Regular bills
  - Make a list of all regular bills and the amounts
    - o Use the check-writing record, check stubs, or cancelled checks to start the list
      - For a fee, the bank could provide you with photocopies of the last few months of cancelled checks
    - o Add to the list as the bills come in over the next few months
    - o Include a list of taxes and tag fees to be paid on the car and when they are due (NOTE: Host or guest presenter can provide some of this information to caregivers by calling the Department of Motor Vehicles prior to this module)
  - Make a list of all credit cards, their numbers and the numbers to call if the cards are stolen; keep the list in a file at home

- If this is not done, the card number and sometimes the number to call if the card is stolen is on the monthly bill

- Occasional bills
    - Medical expenses
        - Confirm that they are in fact bills to be paid, not a summary of charges being paid by insurance
            - The statement will say somewhere, not always very obvious, "This is not an invoice"
        - Check over the bill item by item to be sure it is accurate
            - If caregiver has any questions, don't hesitate to call the billing office, or have someone call, and stay on the phone until all questions are answered
    - Necessary expenses
        - If the budget is too tight to pay a bill in full, pay some amount and include a note explaining an intention to pay regularly until bill is paid
            - Most businesses will appreciate the effort and be understanding
            - Paying a little each month might prevent a computer from registering "no payment" and sending a "past due" notice, even though part of the payment is still past due
    - Income taxes
        - Adjust deductions so that care recipient neither pays nor receives a lot of money at the end of the tax year
            - Have the money earn interest for the care recipient, not the federal government
            - Look at tax deductibility of home improvement or home modifications, such as staircase elevator, widened doorways, etc.
- Automatic bill paying
    - Advantages
        - Bills aren't forgotten
        - Bills are paid on time
    - Disadvantages
        - Might be harder to keep track of
        - Less flexibility in when, or if, the bill is paid
    - Options
        - Through some banks, certain bills can be paid automatically out of a checking account, such as utility bills
        - Some companies can put charges on a credit card, for example, a telephone company
        - Hire an accounting firm to receive and pay the bills
- Consolidation of expenses
    - Check alternatives to using credit cards to stretch a monthly budget
        - The interest charges on unpaid card balances are substantial

- Options
  - Borrow from family or friends, sign a formal loan note, pay reasonable interest, which will be less than a credit card interest rate
  - Borrow against an insurance policy if it has a low interest rates
- Cut unnecessary expenses
  - Be aware of potential impact on care recipient if changes are made
    - A regular membership fee at a facility which care recipient will no longer be able to use
    - A car which care recipient can no longer drive
      - Better to sell it before it has been sitting idle for months
      - No need to pay license and tag fees, and insurance if it is NOT GOING TO BE DRIVEN by anyone
        - Make sure it will not be needed as a second car for some other family member
        - If fees and insurance are stopped, BE SURE TO RE-REGISTER THE CAR if it is ever going to be driven again
      - Don't be pressured into giving car away if the money is needed from selling it
    - A credit card with a fee which care recipient will no longer be using
    - Magazine or newspaper subscriptions which will no longer be read

- Writing and cashing checks
  - Distribute 4 pages from AARP's booklet on handling checks, if desired
  - If caregiver cannot get to a bank
    - Deposits can be made by mail using bank-by-mail envelopes
    - Get cash at the grocery store
      - Most stores, if a check-cashing card is on file, will allow a check for groceries to be written for some amount of cash more than the amount of purchase
      - If someone shops for caregiver
        - Let shopper pay for the groceries and get the extra cash
        - Care recipient can write shopper a check for the groceries plus cash

Income

- Make a list of all sources of income
  - Amounts
  - When the checks arrive
  - Whether the source is good indefinitely or only for a limited time. For example, payment to care recipient for property will eventually end
  - Whether new income is expected in the future

        - Withdrawals from IRA
        - Social Security benefits
- Automatic financial options
    - Automatic deposit of Social Security checks to care recipient's account
    - Representative Payee Program
        - Care recipient designates a Representative Payee to receive the monthly Social Security or Social Security Disability payments and use them on his or her behalf
        - Accurate records of expenditures must be kept
- Untapped potential financial support (NOTE: some of these benefits may be available but information on them may not be volunteered; caregiver may need to know about them to ask about them)
    - Veterans' benefits if qualifications are met, including
        - Dependency and indemnity compensation for parents of veterans who died after December 31, 1958
        - Pensions for needy veterans, their dependents and survivors
        - Veterans - dependency and indemnity compensation (spouses and children)
        - Nursing home benefits
        - Two weeks of free respite care if certain criteria are met
    - Employer benefits
        - Retirement pension
        - Payment for unused vacation time
        - Disability payment
        - Workers' compensation
        - Insurance policies
        - Any special payments by employer for taking care of the care recipient/employee at home
    - Social Security
        - Social Security retirement benefits
            - For persons age 62 and over who have worked the required number of years under Social Security
            - If benefits are received before the age of 65 the benefits will be reduced
        - Social Security survivor benefits for widows, widowers, or divorced spouses under a variety of conditions
        - Social Security Disability Insurance based on degree of disability and number of years worked under Social Security coverage
        - Supplemental Security Income for the financially needy person 65 or older, for the blind, and for the disabled
        - Medicare (distribute "Information on Medicare and Health Insurance for Older People" and, if available, "Your Medicare Handbook")
            - What Medicare is and who is eligible (AARP's booklet, pg 4)

        - How one enrolls in Medicare (AARP's booklet, pg 4)
        - What Part A of Medicare covers (AARP's booklet, pg 5, 7-10)
        - Hospice coverage under Medicare (AARP's booklet, pg 6)
        - What Part B of Medicare covers (AARP's booklet, pg 11-13)
        - List of Medicare insurance carriers by state to contact about Participating Physicians (Social Security booklet, pg 56-64)
            - Each carrier has a toll-free number for calls about Participating Physicians
        - What the difference is between skilled nursing care and custodial care (AARP's booklet, pg 13)
        - Where to go for assistance
            - To find out if a health service provider is Medicare-approved, ask the health care provider directly
            - To the Social Security office to determine eligibility for federal benefits, for assistance with the Participating Physicians Program, to file appeals
            - Contact the state Peer Review Organization to ask what steps can be taken if you feel care recipient is being discharged too soon from the hospital
- Personal insurance policy benefits
    - Disability insurance
    - Low-interest loans from old insurance policies which may offer loans that can be taken out against them at low interest rates fixed years ago
    - Supplemental insurance policy, if you have one, to pick up some of the costs not covered by Medicare, among which may be:
        - The deductible
        - The charge beyond what Medicare approves as reasonable
        - The 20 per cent of the approved charge Medicare doesn't pay
        - The items Medicare doesn't cover at all, for example prescription drugs
        - To decide on suitable supplemental insurance
            - The consumer education program of the state insurance department may help
            - See AARP's "Information on Medicare and Health Insurance for Older People," pages 16-22
- State benefits
    - Medicaid (see pg 23-24 of Information on Medicare and Health Insurance for Older People)

- What Medicaid is
  - A national health assistance program run by the states and supported in part by Federal funds
- Eligibility requirements
  - Vary from state to state
  - In general, needy persons over 65, blind, and disabled
  - Available to most aged, blind, and disabled persons who receive Supplemental Security Income

(NOTE: host should get information on the state rules for eligibility prior to this module since requirements vary from state to state)

- What services are covered
  - Doctor, hospital, and skilled nursing home care
  - Laboratory and X-ray services
  - Home health care services
  - Rural health clinic services
  - Additional services at the option of each state
- All the places to go locally for information

- Miscellaneous
  - Fuel assistance
    - Some local utilities solicit donations from regular customers to create a fund for needy customers
    - Weatherization assistance program insulates homes of low-income persons to cut utility bills
  - Housing assistance
    - Interest reduction payments
      - To lower the costs of rental and cooperative housing for low and moderate income persons
    - Low-income housing - home ownership assistance
      - To reduce interest costs on insured market rate home mortgages
    - Rural rental assistance payments
      - To reduce the rents paid by low-income families occupying eligible housing projects financed by the Farmers Home Administration
  - Food assistance
    - Meals-on-Wheels
    - Distribution of food to needy families
    - Food stamps
      - Eligibility based on income, assets, and work status
    - Nutrition for the elderly

        - Meals served at congregate sites where the social aspect is a bonus, such as at senior centers

Reorganization of finances
- If care recipient has a lot of assets to consider (property, savings in regular or mutual fund accounts, stocks, a company, insurance policies, etc.) caregiver may want to seek professional help
    - Financial planner
        - Make sure financial planner is reputable
            - Get recommendation from a friend
            - Get recommendation from a bank
        - Will look at all assets and expenses
        - Make recommendations as to steps to take for financial security
        - The expense of this service may be offset by better organization of assets and money saved therein

SUMMARY FOR PRESENTATION ON MODULE #5
ON
FINANCES

GOALS
- o Provide caregiver with tools
- o Suggest financial options

EMOTIONS
- o Care recipient feeling
  - hurt
  - angry
  - resentful
  - scared
  - selfish
- o Caregiver feeling overwhelmed

GETTING A GRIP ON FINANCES (80 minutes with a 10-minute break after 40 minutes)

Care recipient can no longer handle finances
- o Don't put off change in financial management
- o Involve care recipient in decisions
- o If care recipient won't give up control

Caregiver needs help with finances
- o Help from family or friends
- o Help from a bank

Expenses
- o Regular bills
- o Occasional bills
- o Automatic bill paying
- o Consolidation of expenses
- o Check processing

Income
- o List all sources
- o Automatic financial options
- o Untapped potential financial support
  - Veterans benefits
  - Employer benefits
  - Social Security
  - State benefits
  - Personal insurance policy benefits
  - Miscellaneous

Reorganization of finances

GUEST PRESENTER'S OUTLINE FOR MODULE #6
ON
MANAGING THE PRESENT, PLANNING THE FUTURE

The GOALS of Module #6 are to:

- Discuss ways to be good consumers of health and legal services;
- Help caregivers, while still in this program's supportive environment, accept the present and begin making concrete plans for the future including
  - inability to continue caring for loved one at home
  - preparing for death of care recipient;
- Provide answers and resources for legal issues.

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does

- Caregiver feeling
  - anxious or guilty about the relationship with the family doctor
  - grief as the care recipient becomes more dependent
  - guilty about resorting to nursing home care
- Caregiver or care recipient
  - being guided in decisions only by loyalty

MANAGING THE PRESENT, PLANNING THE FUTURE (80 minutes with a 10-minute refreshment break after 40 minutes)

Be a good consumer

- Caregiver should learn about the care recipient's medical problem
  - The more caregiver knows about the disease process and ideas on how to cope
    - The less stress and emotional upheaval there will be from unexpected events
    - The better equipped caregiver will be to know what physical, emotional, and medical support will be needed
- Learn to write down and ask critical questions
  - Of the doctor (for example)
    - Does the doctor accept assignment?
    - Questions about medications (will be covered in Module #7)
    - Questions about hospital care
      - Does care recipient have to go into the hospital or can the problem be taken care of as an outpatient?
      - Are there alternatives to the suggested treatment?
      - What is the complete diagnosis and prognosis?

Caregiver may be feeling ANXIOUS or GUILTY

If caregiver is unhappy with the kind of treatment the doctor is providing it may be difficult to consider switching to another new doctor, especially if the caregiver and care recipient have been going to this doctor for years. The caregiver will be afraid of hurting the doctor's feelings, afraid to make a statement that says "I don't think you are doing a good job." There will also be a feeling of anxiety about getting to know another doctor.

The caregiver needs to decide which is most important - the care being provided, or the feelings of the professional. The physician may not even experience the feelings the caregiver is anticipating. If a decision is made to change health care professionals, plan the move. Ask friends, or other professionals you are dealing with if they can recommend a doctor; talk to the doctor first; then ask the new doctor to request a transfer of medical records. Remember, you never signed a statement with the first doctor that you would be his or her patient forever, just like you never do with a beautician, a car repairman, or a grocery store. You deserve your money's worth.

- Of the home health agency (for example)
    - o What are the qualifications of the staff?
    - o What will the service cost?
    - o What does the agency expect the aide to do in the home?
    - o Is the aide to perform set duties or stay for a set amount of time?
    - o What else can the aide be asked to do?
    - o What is the process if the aide is not doing what is expected?
- Of yourself
    - o Is the health professional answering all questions?
    - o Is the health professional dealing well with both the physical and emotional needs of the care recipient?
    - o Is caregiver happy with the service being rendered?

(ASK CAREGIVERS TO ADD TO THESE QUESTIONS)

- o Tell the health care provider all the helpful information
    - The community resources the care recipient is taking advantage of may need to be taken into account by the doctor
- o Comparative shopping for health care
    - You would find a new business to patronize if the beautician or car repairman
        - o Gave you an end product you did not like
        - o Abused your feelings even if the end product was good
    - Health care should be no different

    - Make a list of potential health care providers
    - List the things you need to know about their services in order of priority
  - Choose the provider which is best for caregiver and care recipient
    - Don't let the professionals, family, or friends pressure you into a choice with which you are not comfortable
- Know your rights
  - Medical records
    - Reasons for wanting to see them
      - To transfer records for treatment elsewhere
      - Records might contain misinformation which needs correcting
      - For better understanding of medical condition if you have all the information
        - Medical records often contain a lot of abbreviations and technical information which may require clarification by a health professional
      - Curiosity
    - Right to see them
      - About half of the states have laws governing access to non-mental-health medical records
      - The laws vary from state to state, for example in some:
        - You can inspect but not copy
        - You can have access only to summaries
    - If your request to see them is denied, ask your doctor for information on what your state laws are on the issue; you may get medical records instead
    - Write a letter to your state legislative representative indicating why you feel you should have access and send a copy of the letter to your physician/hospital. A patient has a right to know the facts in order to make an informed decision.
    - Ask your lawyer to request the records for you
  - Hospital stay
    - Some hospitals may have a Patient's Bill of Rights; ask if yours does when your care recipient is checked in
      - A statement of what a patient can expect from the institution
      - If there is a problem the nurses can't solve, ask if the hospital has a Patient Representative who can help you
    - Know how to contact the state's Peer Review Organization should care recipient's length of stay in the hospital be questioned
      - Medicare does not say when a person has to be discharged, a doctor does
        - Your doctor may be pressured by the hospital to release patients

- Although the process is complex, if caregiver feels care recipient is being discharged too soon an appeal can be made to the PRO which will decide about the discharge
  - o Locate PRO through
    - Regional Health Care Financing Administration (HCFA) office (federal government)
    - The hospital administrative office

REFRESHMENT AND STRETCH BREAK OF 10 MINUTES

Planning the future

- o Advance directives
  - The pre-planning, no matter at when it is done, will avoid the time-consuming and sometimes costly involvement of guardianship, family disagreements, or the court

Caregiver may be feeling GRIEF

When the health of the care recipient worsens and he or she is less and less mobile, the grieving process begins for the caregiver. The reality of needing to begin letting go of the care recipient cannot be ignored. At a point where caregiver may most be in need of support, friends are having a hard time with the situation. The caregiver is not a widow or widower, nor is he or she able to be out much socializing even if the caregiver wanted to be. Friends are afraid to call because they would have to ask about the care recipient but don't want to make the caregiver focus on the fact that the care recipient isn't getting better.

Caregiver may need to empathize with how difficult the friends are finding the situation and seek them out. Be open about how you just need someone to talk to, or whatever. Once approached the friends will probably be glad to help out any way they can.

  - Options
    - o Will
      - Every adult should have an up-to-date will
      - Getting will written need not be expensive
        - o Options other than personal lawyer
          - Legal clinic
          - Legal Services for the Elderly
          - Suggestions from the Agency on Aging

  - Living will
    - Document for the terminally ill stating desires regarding life-support medical treatments which might prolong life; must be signed, dated, and witnessed
    - Living wills are recognized by statutes in about 35 states
      - Statutes validating living wills vary greatly from state to state
      - Where there is no state statute it is still useful as an advisory document
    - 38 states and the District of Columbia have laws to provide immunity for health care professionals who comply with living wills
    - Entrust copies of living will to your doctor and a close family member or friend, not a bank safe deposit box where it would not be found until after death
- Delegation of decision-making power
  - Choosing someone else to legally act for care recipient
  - Choose the representative carefully, not by who it should be but by who is best to be representative

> Care recipient or caregiver may be feeling guided by LOYALTY to the oldest child
>
> If one of the children is to be named the official representative for the care recipient, the choice should be based on how well the task can be handled by that child, not on who is oldest, or who is expecting or wanting to be named the representative.

  - Options
    - Power of attorney (a written document by which care recipient appoints someone else as his/her agent and confers upon that agent the authority to act in place of the care recipient for the purposes stated in the document)
      - Arrange before it is too late
        - Care recipient must be mentally capable of understanding the degree of power she or he is turning over
      - Responsibility can go to friend or family member
      - The "agent" must be noted in writing, document must be signed by the care recipient, and, depending on the relevant state law, notarized
        - Written document can grant as broad or as narrow a range of powers as wished

  - May be revoked at any time by care recipient or may be revoked automatically upon death of the care recipient, or when it expires according to its own terms
- Durable power of attorney (differs from power of attorney in that it remains in effect even if the care recipient later becomes incompetent)
  - Valid everywhere in the United States
  - Relatively simple to create but state law should be consulted for specific state requirements
  - Care recipient must be mentally capable of understanding the degree of power she or he is turning over
  - Can only be revoked by the care recipient, by a legal declaration that care recipient is incompetent (except in the case of a "springing" power of attorney - discuss this with a lawyer), by death of care recipient, or by the terms of the way the durable power of attorney was set up
  - Traditionally used to provide for property management
    - Its use in terms of health care decisions
      - Should state "durable power of attorney for health care decisions"
      - Legal in a few states, not legal in a few; use in all other states is unsettled
      - Unlike power of attorney, would stay in effect if care recipient slipped into a coma, for example
- Revocable living trust
  - Care recipient, while mentally competent, transfers ownership of all his or her property to a self-benefitting trust
  - Allows care recipient to retain control over his or her affairs while competent, but provides for trustee should she or he become incompetent
  - Major disadvantage is the cost associated with creating and managing revocable living trust
- Guardianship (where one individual becomes a substitute decision maker for another)
  - Guardianship is controlled by state law and varies from state to state
  - Some states authorize a guardian of the person (responsible for personal and health care decisions) and a guardian of the estate (responsible for property management)

            - A court declares that care recipient is unable to perform essential life functions resulting from a lack of mental capacity and appoints a guardian to manage care recipient and his or her affairs
            - Court-appointed guardian must file annual financial reports with the court and, therefore, manage the affairs of the care recipient wisely
            - Care recipient may lose some or all civil rights such as right to vote, drive, sign a contract, change or write a will, marry or divorce, live and go where she or he wants, make decisions about his or her own health care
        - Limited guardianship
            - An option in many states
            - Only specific powers over the care recipient are transferred to guardian
        - Proxy consent
            - A close relative is designated to give proxy consent in specific medical care situations
                - This is traditional, common, and usually done in collaboration with health care professionals
            - It is the option least likely to be legally valid in most states and situations since only about 12 states have laws governing proxy consent
- Legal resources
    - For persons unable to afford legal assistance for matters of a noncriminal nature
        - Legal clinic
        - Legal Services for the Elderly
        - Suggestions from the Agency on Aging
- Options for care other than in the home

Caregiver may be feeling GUILT

If home care becomes impossible - the caregiver is too frail to move the care recipient, the caregiver cannot cope with so little sleep or the incontinence, or for some other reason - and a decision must be made to put the care recipient in a nursing home, the caregiver may feel guilty. The care recipient may have been promised that he or she would never be put in a nursing home, so now the caregiver is breaking a promise. Or the caregiver feels he or she ought to be able to manage at home yet, but just can't. To put the care recipient into a nursing home feels like not providing the best care which is owed the care recipient. On the contrary, the nursing home will be able to provide critical care and the caregiver will have the energy to supplement that care with personal attention to the care recipient. Also, if frequent visitors can be scheduled it will feel less to the care recipient like he or she has been abandoned, and will help the caregiver feel less guilty about having placed the care recipient in the facility.

- Choosing a facility
  - Don't wait until a change in the home care has to be made to check out the options
    - Caregiver will feel better if decision is not made under pressure and all options have been considered
  - Decide to what extent the care recipient will need help
  - Make a list of facilities in the area that will meet the needs of the care recipient
  - Suggestions for reviewing options
    - Impromptu assessment of facility
      - Arrive after 11 AM so staff has had time to do routine tasks
      - Staff may have less time for you but you will see things as they normally are at the facility
    - Signs of well-run facility might include:
      - Being told that you may look around freely
      - Finding the residents dressed
      - The residents appearing happy
      - The facility appearing clean
    - Come with a list of questions, add to the list as you look around, ask if you can speak with the administrator to get those questions answered
      - Ask what the entry requirements are
      - Find out what kind of activities there are for residents
      - Ask about the potential for rehabilitation so the care recipient might come home again, given the disease process and the facility's resources

Caregiver may be feeling RELIEF

Once the decision is made to place the care recipient into a partial or total care facility, the caregiver may feel relief - from not having the burden of care, from being able to get back to a more normal life. If the nursing home has a good rehabilitation department, the decision to place the care recipient was probably easier knowing the care would be so good and that maybe the care recipient would not spend the rest of his or her life there. However, after experiencing the relief of not being the primary caregiver, accepting that responsibility again if the care recipient improves and is sent home is even more difficult.

The caregiver needs to be realistic about possibilities that the care recipient might improve, or that he or she might not, and plan accordingly.

- Financing long-term care
  - Insurance is becoming more widely available for financing long-term care that doesn't qualify under Medicare and is available for persons who don't yet need long-term care services
  - Speak to an attorney at the earliest possible time about how to arrange your finances in the event that care recipient should have to be put in a nursing home eventually
    - Being able to make some changes two years in advance of moving care recipient to a nursing home might be advantageous
      - In some states the entire income of both a husband and wife is looked at as assets solely for the one going into the nursing home
      - The result is that the one not going into the nursing home may have very little money to live on; in some cases homes have had to be sold to finance the nursing home costs

SUMMARY FOR PRESENTATION ON MODULE #6
ON
MANAGING THE PRESENT, PLANNING THE FUTURE

GOALS

- o Discuss ways to be good consumers
- o Help caregivers accept the present and plan for the future
  - inability to continue caring for loved one at home
  - preparing for death of care recipient
- o Provide answers and resources

EMOTIONS

- o Caregiver feeling
  - anxious
  - guilty
  - grief
- o Caregiver or care recipient being guided by loyalty

MANAGING THE PRESENT, PLANNING THE FUTURE (80 minutes with a 10-minute refreshment break after 40 minutes)

Be a good consumer

- o Learn about medical problem
- o Learn to ask critical questions
  - Of doctor
  - Of home health agency
  - Of self
- o Give complete information
- o Shop for health care
- o Know your rights
  - Medical records
  - Hospital stays

Planning the future

- o Advance directives
  - Pre-planning options
    - o Will
    - o Living will
  - Delegation of decision-making power
    - o Power of attorney
    - o Durable power of attorney
    - o Revocable living trust
    - o Guardianship
    - o Limited guardianship
    - o Proxy consent

- o Legal resources

- o Options for care other than at home
  - Don't wait to check options
  - Suggestions for reviewing options

- o Financing long-term care

GUEST PRESENTER'S OUTLINE FOR MODULE #7
ON
MEDICATIONS

The GOAL of Module #7 is to:

- o Stress the importance of the effects of medications and taking them properly

MEDICATIONS (45 minutes)

Aging versus side effects

- o Signs of aging
  - Everyone does not age the same way
  - Common changes in some older persons are
    - o Moving more slowly
    - o Body less flexible
    - o Hearing becoming less acute
    - o Vision worsens
    - o Sense of smell and taste less acute
- o Side effects are generally undesirable and may occur as a result of medication
  - Recognizing medication side effects
    - o Ask the doctor or pharmacist which ones to expect
    - o Because people may react differently to the same medication, any unexpected behavior should be noted as a possible side effect
    - o Keeping a journal may help you
      - Notice medication side effects because of a certain pattern developing
      - Answer a physician's/pharmacist's questions more accurately. For example:
        - o What time of day was the behavior/ reaction?
        - o How long after eating/exercising/being in the sun?
        - o What was eaten and drunk?

Taking medications made easier

- o Help care recipient be responsible for taking his or her own medications for as long as possible
  - Put raised identification letters/numbers which can be felt on top of pill bottles if vision is poor
  - If care recipient is home alone, call to remind him or her that it is time to take a medication
  - Put pills in cup to put into mouth, rather than in hand, to prevent dropping
  - Use a medicating system (for care recipient, for caregiver, for others who might be involved)
    - o Plan medications as part of a very set routine so that the same thing is done every day just before and after taking medications
    - o Each morning set out all pills for that day; make sure care recipient doesn't take them all at once

    - Make a large, easily read wall chart to show what medications are to be taken on what day at what time; glue/tape an actual pill beside the name of the medication
    - Take medication that is to be taken every other day "odd days" or "even days" of the month; post a sign where the pills are taken to remind everyone whether it is an "odd" or "even" month; switch at the end of each month with 29 or 31 days in it
    - Have pharmacist prepackage care recipient's daily medications in blister packages (all morning medications together in one foil-backed plastic slot, for example)
  - Purchase special measuring and dispensing tools such as divided pill holder with sections for hours in the day or days in the week (or make one from an egg carton)
- Taking medications away from home
  - Have pharmacist split one medication prescription into two bottles so care recipient can take medication in an original pharmacy container to adult day care, for example

Preventing and handling medication problems

- Ask doctor or pharmacist about every medication
  - Are there alternatives to taking the medication?
    - Lose weight rather than take blood pressure medication?
    - Go on a salt-free diet rather than taking "water pills"?
  - Will the doctor prescribe the generic version? (Generic drugs are chemical equivalents to brand-name products that can sell for up to 50 percent less.)
  - Why is it important to take the medication?
  - How much of the medication is to be taken, how often, and for how long? (It is important to know when to stop taking a medication.)
  - Are there special storage instructions such as not exposing to air or needing refrigeration?
  - What does the medication do?
  - How does the medication work?
    - Released over time?
    - Take effect immediately?
    - Have cumulative effect?
  - When and how should the medication be taken?
    - Unless otherwise indicated it is usually best to take medicine on an empty stomach with 8 ounces of water ("empty stomach" means 1 hour before or 2 hours after a meal)
    - Some medications that irritate the stomach or are better absorbed with food are directed to be taken with meals
      - "With meal" means just before, during or just after a full meal
      - If the medicine must be taken between meals, take it with milk or some sort of snack

    - What are the potential side effects and why are they taking place?
    - What foods, drinks, or other drugs should be avoided (get a complete list)?
    - What to do if a dose is missed, or two doses are taken accidentally?
    - Should any unused medication be saved for future use?
- o Importance of medicating properly
    - Follow medicating instructions exactly for maximum benefit
        - o Even if it is not convenient
            - Care recipient may be on a water pill which means going away from a bathroom is out of the question
        - o Even if caregiver's personal assessment is that the dose or time of medicating should be changed
        - o Even if there is an urge to save money by taking the medication less often, by taking a half dose or by taking a medication the date of which has expired
    - Contact your doctor or pharmacist
        - o If you notice any unexpected or dangerous side effect
        - o If you want to change the medication schedule or dose but don't know what the effect would be
            - A particular medication makes the care recipient sleep; it would be nice to change the time it is given so that the sleep time fits better into caregiver's schedule
            - It would be more convenient to give the diuretic just after a set weekly outing, rather than just before it
        - o If you don't understand something about the medication
        - o If a problem has come up that a new medication might help
            - Care recipient forgets to blow his or her nose; doctor can prescribe a medication to relieve the congestion
- o Obtaining medications
    - Have medications delivered to home
    - Have medications mailed to home
    - Use drugstores that are open 24 hours
- o Keeping medication costs down
    - Ask the doctor or pharmacist for a generic substitute if available
    - Price the same medication at 2-3 drug stores (this can usually be done by phone)
    - Have a personal drug profile done on care recipient by a pharmacist to make sure there are no drugs working against or duplicating each other

SUMMARY FOR PRESENTATION ON MODULE #7
ON
MEDICATIONS

GOALS
- Stress the importance of the effects of medications and taking medications properly

MEDICATIONS (45 minutes)

Aging versus side effects
- Signs of aging
- Side effects
- Recognizing medication side effects

Taking medications made easier
- Help care recipient take medications on own
- Taking medications away from home

Preventing and handling medication problems
- Information to get from doctor or pharmacist
- Importance of medicating properly
- Obtaining medications easily for the least expense

GUEST PRESENTER'S OUTLINE FOR MODULE #7
ON
NUTRITION

The GOAL of Module #7 is to:
- Provide practical tips on dealing with the nutritional problems of the care recipient

NUTRITION (45 minutes)

Nutritional requirements of well older persons
- Discuss Basic Food Groups (you can refer to pages 39-40 of AARP's turquoise Additional Resources booklet if caregivers are using it in this course)
- Nutrients needed are basically the same as for younger person with women especially making sure they get enough calcium and iron
- Generally fewer calories needed due to less active life
  - Usually achieved by cutting down on foods from "Other" group
    - Sugar-laden foods
    - fat-rich foods
    - Alcohol
- Plenty of fiber is needed from fresh fruits and vegetables and whole grains

Additional nutritional needs of care recipient if appetite is poor, decreases, or ceases
- Look for potential causes
- Try various solutions
  - Have care recipient eat with others in a more social setting
  - See if dentures fit too poorly for care recipient to eat easily, especially if care recipient has lost weight recently
  - Serve 6 smaller meals rather than 3-4 regular meals
  - Try more herbs or spices for flavor, especially if care recipient has dentures and can't taste as well
  - Serve one food at a time rather than the whole meal, beginning with the most nutritious item; an especially important technique for Alzheimer's victims who tend to eat too fast
  - In case care recipient is having trouble swallowing or using his or her hands, try cutting food, or cutting it into smaller pieces
  - Add fresh flowers, some nice music, good china and a cloth napkin at mealtime
  - Allow lots of time for eating
  - Fix the care recipient's favorite food, and increase the nutritional value of it before serving
- Increase nutritive and health value of what is eaten (if not contraindicated by special diet)
  - Increase calcium and protein, with few additional calories, by mixing powdered skim milk into foods

  - Increase calcium and protein, with few additional calories, by cooking rice in skim milk, not water (use double boiler to prevent scorching)
  - Add protein to cooked foods or drinks by adding an egg or wheat germ (available in the cereal section of the grocery store)
  - Serve more nutritious drinks, even if incontinence is a problem
  - Use a nutritional supplement
  - Add fiber to foods by mixing in, or sprinkling over, wheat bran
- Increase caloric value of food to prevent weight loss (if not contraindicated by special diet)
  - Cook, or fix drinks, with whole milk
  - Add finely chopped or ground nuts, which are high in fat and therefore calories, to other foods
  - Serve peanut butter and olives which are high in fat and therefore calories
- Prepare foods so consistency is softer
  - If dentures can't be worn all the time
  - To prevent choking if care recipient has trouble swallowing (a problem for Parkinson's sufferers),
  - If digestive system can't handle bulk
  - Soften only as much as necessary to maintain as much bulk in diet as possible
    - Cook vegetables with minimal amount of liquid, or steam them, until soft to retain nutrients
    - Mash fruits and make creamier by adding a little vanilla yogurt
    - Finely shred beef or chicken by grating a fork over it, or flake fish, for protein
    - Serve peanut butter or cheese for soft protein
- Maintain care recipient's ability to feed self as long as possible
  - Serve acceptable adult "finger foods" if handling utensils becomes difficult
    - Dairy products
      - Wedges, sticks or cubes of cheese
      - Frozen yogurt on a stick
      - Grated cheese held together with a little bit of yogurt (to serve on crackers)
    - Meats or substitute
      - Hard boiled eggs
      - Chicken baked without a sauce on it
      - Rolls of thin-sliced poultry or meat
      - Shrimp
      - Fish sticks
      - Tuna spread (to serve on crackers)
      - Nuts and seeds
    - Grains
      - Whole grain, low-salt crackers
      - Rolled tortilla (with meat and/or cheese inside)
      - Toast, muffin, bagel

      - Pizza
    - Fruits/vegetables
      - Raw vegetable sticks with cottage cheese dip
      - Wedges of fruit
  - Use glass, plastic or paper flexi-straws for liquids
  - Crinkle clean napkin to make it easier to grab
  - Put a wet paper towel between plate or dish and table to prevent sliding
  - Tie a large apron around care recipient's neck; put bottom of apron on table under the plate so dropped food will be caught
  - Make changes to aid care recipient with failing vision
    - Serve light colored foods (potatoes, corn, cauliflower, rice, chicken, fish, squash, cottage cheese) on a dark colored plate
    - Serve dark foods (beef, green vegetables, dark bread, beets) on a white plate
      - Take special plates when eating out; restaurants and friends will understand
    - Tell care recipient where food and drinks are at table setting by relating to clock face; meat is at 11, peas are at 5, water is just beyond 2
    - Add extra light in eating area
  - Special utensils for physical eating obstacles
    - Adaptive feeding spoon
    - Two-handled mug
    - Cup with lid
    - Suction plate
    - Dishes with lip
- Avoid dehydration
  - If diarrhea occurs, make sure liquid intake continues to replace the large amount of liquid being lost
- Be aware of Heimlich maneuver to deal with choking on food (these should be demonstrated to caregivers)
  - Technique if care recipient is bed-bound
  - Technique of doing it to one's self
  - Technique if care recipient is capable of standing

Special diets

- Get assistance from a dietitian, qualified nutritionist or doctor before beginning a special diet
- Learn to read food content labels to assure yourself of what you are eating
- General tips
  - Reduce salt
    - Do not add salt in cooking
    - Buy foods marked "unsalted" or "low-salt"; a label of "50 percent less salt" is useless to shopping carefully unless you know how much salt the product had originally
    - Buy basic, raw ingredients, not prepared foods and dressings
    - Don't buy foods with salt in "disguise"
      - Sodium nitrite
      - Sodium benzoate

        - Monosodium glutamate (MSG)
        - Sodium bicarbonate (baking soda)
        - Sodium phosphate
    - Use a salt substitute
    - Season vegetables with fresh lemon juice or herbs
    - Rinse canned vegetables that contain salt
- Reduce fat
    - Milk products
        - Use blended low-fat cottage cheese or yogurt rather than sour cream for dips, baked potatoes, and salad dressings
        - Drink and cook with skim milk
        - Reduce consumption of cheddar and cream cheeses
    - Meats and substitutes
        - Reduce consumption of red meats and bacon
        - Cut off all visible fat
        - Eat fish, skinless chicken, or meatless meals
        - Bake, broil, steam or pressure cook foods rather than fry them
        - Avoid nuts, peanut butter and seeds
    - Grains
        - Use thin spreads of jam on breads, rather than margarine or butter
        - Serve rice without butter or margarine
    - Fruits and Vegetables
        - Avoid avocados and olives
        - Steam vegetables rather than fry
        - Serve vegetables, including potatoes, without butter or margarine
- Reduce cholesterol, which comes from animals, not plants
    - Use margarine and vegetable oils instead of butter
    - Limit consumption of
        - Organ meats such as liver, giblets, heart, kidneys and tongue
        - Oysters and shrimp
        - Egg yolks
        - Cheddar and cream cheeses
        - Heavy whipping cream
- For diabetics
    - Reduce caloric intake to reach and maintain a recommended weight
    - Decrease consumptions of sugars
        - sugar
        - corn syrup
        - dextrin
        - dextrose
        - fructose
        - galactose
        - sucrose
        - sorbitol
        - molasses
        - lactose
        - honey
        - glucose
    - Increase consumption of starches such as breads and potatoes

- Serving other family members the "special" diets is a healthier way of eating that almost everyone can benefit from
  - Other family members eating the "special" foods might make it easier for caregiver, and the care recipient would have less tendency to feel guilty about creating problems
  - Work other family members in to the "special" foods gradually
    - Low salt
      - Have salt at the table if it must be added but encourage less and less use of it
      - Some salt is necessary but salt doesn't need to be added to food to get what little the body requires
    - Low fat
      - Gradually increase the low-fat proportions in foods for other family members until low-fat alone tastes good to everyone
        - Week by week mix skim milk with whole milk in increasingly larger proportions
      - Skinned chicken baked with a coating of parmesan cheese and seasonings (such as tarragon and garlic powder) is a good substitute for fried chicken
    - Diabetic
      - Increase for everyone the amount of fresh or canned fruit desserts and decrease cookies, pies, cakes, candy
      - In dessert recipes, cut the amount of sugar that is called for to 1/2 to 2/3 of the original
- Cooking techniques to mesh two diets
  - Freeze individual servings of special foods for care recipient
  - Freeze an entire meal on a divided, heat resistant plate or tray
  - If no microwave oven is available, heat or cook open foil packets of different foods together in a pressure cooker for 10-12 minutes (for example, frozen macaroni and cheese will thaw and heat, slices of carrot will cook, and potatoes for the rest of the family will cook)
  - Plan meals where all things bake, or broil

SUMMARY FOR PRESENTATION ON MODULE #7
ON
NUTRITION

GOAL

- Provide practical nutritional tips

NUTRITION (45 minutes)

- Nutritional requirements of well older persons
  - Discuss Basic Food Groups
- Additional needs of care recipient
  - If appetite is poor
    - Look for cause
    - Try various solutions
    - Increase nutritive and health value
    - Increase caloric value
  - Change consistency
  - Make food easier to eat
    - Preserve care recipient's ability to eat on own
    - Serve finger foods
    - Use aids
    - Take vision needs into account
  - Avoid dehydration
- Special diets
  - Get assistance
  - Learn to read food content labels
  - General tips
    - Low salt
    - Low fat
    - Low cholesterol
    - Diabetic
- Serving other family members
  - Encourage others to eat special diet
  - Work family members into it gradually
  - Cooking techniques to mesh two diets

GUEST PRESENTER'S OUTLINE FOR MODULE #8
ON
FAMILY INTERACTIONS AND EMOTIONS

The GOALS of Module #8 are to:

- Look objectively at family relationships
- Help caregivers recognize both their emotions and those of care recipient
- Explore constructive ways of dealing with emotions
- Stress the need for relaxation and teach simple relaxation techniques

EMOTIONS to listen for during conversation, reiterate for emphasis, or mention if no one does

- Care recipient feeling - isolated or ignored because of poor hearing
- Caregiver feeling
  - angry or resentful toward unsupportive family members
  - guilty about not wanting to be the primary caregiver
  - angry or anxious about no longer being the dependent person
- Caregiver and care recipient feeling isolated from other family members

COMMUNICATIONS SKILLS (20 minutes)

Care recipient may be feeling ISOLATED, IGNORED

By not being able to hear, the care recipient misses out on a lot and is isolated. Because the hearing problem makes it difficult for others to communicate with the care recipient they often don't try. The care recipient's feeling of self-worth goes down when he or she is never asked for an opinion on an issue, even though it is because of the hearing problem, not because of the value of the opinion.

Try to include the care recipient even when it is difficult. If a known issue needs to be discussed, try to give the care recipient some advance notice about the subject. Have a blackboard on the wall by the table so some key words can be written down for the care recipient to see during a discussion. Ask the care recipient what else others could do to include him or her.

Communication between caregiver and care recipient

- If care recipient is hard of hearing
  - Hearing aid may not always be on; since hearing aids mostly amplify, care recipient may have turned aid off to cut out the background noise
  - Use easy techniques to enhance communication
    - Always call care recipient by name first to get his or her attention before beginning to speak

    - Introduce the conversation topic before asking a question or sharing a thought
        - "Dad, about your wheelchair, I want to see if we can get you a more comfortable seat today."
    - Talk to care recipient only while in the same room
    - Speak to care recipient face to face so she or he can watch your mouth
    - Don't try to talk over background noises like TV, radio, traffic noises
    - If something said was not understood by the care recipient, don't repeat it exactly; try to use different words the second time that may be easier for care recipient to understand
        - Change "I want to see if we can get you a more comfortable seat today" to "That seat is too hard. I want to buy you a softer one this afternoon."
            - NOTE: If care recipient has dementia, exact repetition is preferable to rewording
- Use the sense of touch
    - Remember that care recipient is a person, not a patient, and emotional needs continue, and may even increase, with illness
    - If not overdone, touching can positively reinforce acceptable behavior
        - Don't withhold touching as punishment for unacceptable behavior; simply be more demonstrative for good behavior

Communication with other family members

- Family members in the household or nearby
    - Don't be a caregiver at the expense of your relationship with other family members
    - Plan a regular time each week to get everyone together to share feelings and work on group solutions to problems
        - Have a set agenda so everyone knows what to expect and everyone has a chance to be heard
        - Everyone should plan to share:
            - One thing that happened within the family last week that made them feel good
            - One problem, concern, frustration, etc. that they want help with
                - Don't let the gathering be to air only negative aspects of the situation
- Family members far away
    - If out-of-town family want to help but can't be near, have list of things they can do to help you

Caregiver and care recipient may be feeling ISOLATED from family members who aren't providing care.

Encourage phone calls from the other family members, at the very least. If care recipient seems hard to talk to on the phone, because of inability to respond for example, encourage family member to call anyway but have a written list of little things they can share even without a lot of response. With many care recipients, one never knows when they will tune in or out. The sound of the familiar voice may mean a lot even if the words don't.

- Send money so you can pay for respite care
- Spend part of their vacation providing respite care
- Send baked goods that caregiver does not have time to bake
- Phone care recipient often
  - You can help out-of-town person by cluing him or her as to events care recipient may want to talk about
- Send greeting cards, taped letters, or postcards often
  - The cost of a brief phone call and the cost of a card and stamp are about the same
- Send coupons for items caregiver has to purchase

- If out-of-town family members help very little but persist in telling caregiver what to do

Caregiver may be feeling ANGER and RESENTMENT toward unsupportive family members

Caregiver may feel like other family members are being selfish and greedy by not giving time to help and by not wanting to know how the caregiver and care recipient are doing. The other family members may not know how to help; they may not be able to accept the fact that the care recipient is ill or old enough to need help, a situation that usually puts people in touch with their own mortality and many people can't deal with that. The other family members may be feeling guilty about not helping and their only way of coping with that guilt is to not communicate, to pretend the situation does not exist.

Caregiver should try to figure out why the other family members are not involved, and suggest ways for them to be involved that will make everyone feel better.

- Caregiver should not feel guilty about giving those family members more say in the decisions by being closer to the situation OR to offer their opinion but leave all final decisions to the caregiver

- Dealing with losses
    - A death in the family, or of a close friend, is apt to hit the care recipient harder than others

Relationship between caregiver and care recipient

> Caregiver may be feeling GUILT
>
> Many caregivers feel like they owe the care recipient this care, and feel guilty if they don't really want to provide the care. Some care recipients will also try to make the caregiver feel guilty, in a way they could never do with strangers, by saying things like, "You wouldn't dare (do this, or not do this) to me now that I have had a stroke."

- The caregiver and care recipient usually will relate to each other in the present the way they did in the past (except in the case of a dementia care recipient who will become very childlike)
    - The presence of a caregiving situation usually will not significantly change the way they relate to each other
        - Disappointment over dashed expectations for change on the part of either caregiver or care recipient (care recipient may expect a change because he or she is in poor health and can't fight back for example, or caregiver may expect less nagging because of all the extra homecare work he or she is doing) may interfere with the ability to relate with much needed patience and understanding
    - Role reversal is difficult for both parties

> Caregiver may be feeling ANGER and ANXIETY
>
> After being dependent on someone, and now being depended on, the caregiver may feel anger at being deserted. Also, anxiety is not unreasonable as the caregiver starts learning how to make decisions for both himself or herself and another person.

- When the parent, who has always taken care of and advised the child, becomes ill and the child is the caregiver

        - When the wife, who has been dependent on the husband for their married life, is suddenly the caregiver
- Dealing with the sexual relationship
    - Caregiver may be too exhausted from giving care to want sex
    - Care recipient with dementia may not resemble the person caregiver loved during healthier years and making love with dementia care recipient would be like making love to a stranger
    - Try to show affection in other ways, and as often as possible, to prevent care recipient from feeling rejected
- Dealing with personality changes
    - Caregiver needs to realize it is part of disease process and not intentional on care recipient's part
    - Irony is that target of personality changes will most often be the caregiver and other family members who are doing the most for the care recipient
        - Care recipient with dementia or a stroke may hurl insults or swear words
            - "I hate you" may really mean "I hate what is happening to me"
        - As memory fails and items are misplaced by care recipient, he or she may accuse caregiver and express paranoia
    - Care recipient with dementia may experience rapid mood changes which may be caused by brain being overwhelmed with too much noise, by being asked to do something too difficult, or by too many people around
        - Simplify or quiet the situation; use sense of touch to reassure care recipient

Caregiver may feel UNLOVED or UNAPPRECIATED

If care recipient likes an aide that caregiver feels a need to replace for some reason, or whose actions need to be questioned, caregiver may find himself or herself in disagreement with the care recipient. It may seem like the care recipient does not understand how difficult caregiving is, or that the care recipient is ungrateful for all the things the caregiver has been doing.

Try to talk through the problem. Go over why the aide is there to begin with, what is and is not being done of the things that should be, the understanding that the aide is now a friend but maybe is taking advantage of a lax situation, etc. Try to get care recipient involved in the evaluation of the situation and what to do about it so she or he will be more accepting of the outcome.

Relationship between home health aide and care recipient

- Care recipient who has been "worker" all his or her life, as opposed to a "boss", will not be good at directing a home health aide
  - It will be easier to have aide not do tasks than for care recipient to admit dependency and the need to be "waited on"
- Care recipient may trust aide and become friends in part because the aide will be company
  - Advantage is that care recipient may "mind" aide and do things she or he would not do for family
  - Disadvantage is that care recipient may take aide's side and defend the aide against the primary caregiver
- Persons helping care for care recipient should be changed as infrequently as possible to avoid unsettling care recipient

Relationship between home health aide and caregiver

- Keep friendly but businesslike in case there are problems to work out or a new aide needs to be requested

EMOTIONS OF CARE RECIPIENT AND CAREGIVER (60 minutes including refreshment break)

Include in this time frame emotions that may have been skipped in earlier modules, or only partially discussed.

(10 minutes) Distribute "How Is Your Care Recipient Feeling?". Ask participants to reflect on the past week and write about comments the care recipient made, actions she or he took, or moods that might be explained by one of the emotions listed. Offer an example.

(15 minutes) When each caregiver has finished ask for a volunteer to share on one of the emotions she or he responded to. Encourage open discussion with some of the following:

- How would the caregiver handle a similar situation another time?
- Does another caregiver remember a situation when something similar happened to him or her?
  - Important so caregiver doesn't feel like she or he is the only one dealing in this way with care recipient
- Was the caregiver surprised the care recipient was feeling that way?
- Do the caregivers feel like they could talk about some of these feelings with their care recipients?

10-MINUTE REFRESHMENT BREAK

(10 minutes) Distribute "How Are You Feeling?". Ask participants to reflect on the past week and write down the situations in which they felt any of the emotions, whether or not they feel it was justified in the situation, and whether they felt good about their reactions. Offer an example.

(15 minutes) When each caregiver has finished ask for a volunteer to share one of the emotions she or he responded to. Encourage open discussion with the first three questions used for emotions of the care recipient.

BRINGING HOME IS WHERE THE CARE IS TO A CLOSE (30 minutes)

(20 minutes) Ask each caregiver to share his or her greatest joy and greatest concern about caregiving now that the course is coming to an end. Make sure they leave with some resource to deal with the concern.

Distribute evaluation forms and addressed, stamped envelopes.

Make sure caregivers know what the topic is for their ninth (specific-needs) module, and where they will be doing it.

(10 minutes) End with demonstration of relaxation technique
- o Caregiver can do at home to relieve stress
  - Take a few minutes, in a quiet room and imagine places caregiver is fond of
- o Mental imagery to give caregivers example
  - Have caregivers lie on mats on the floor in a position comfortable for them with their eyes closed
  - Dim the lights a little if possible
  - Play some slow, soft music that will run about 8 minutes
  - Ask the caregivers to take 4 slow, deep breaths paced by the host, "inhale . . . exhale . . . inhale . . . exhale, etc."
  - Then in a soothing, unhurried voice, help caregivers' imaginations take them away to some place comforting; as you describe the setting, leave time between images so the caregivers have time to personalize the experience in their mind's eye
    - o An example might be, "You are wearing your favorite and most comfortable outfit of casual clothing . . . it is a glorious spring day. . . the sun is warm on your skin. . . you are walking slowly through a field of grass swaying in a gentle breeze. . . ahead you see a brilliant array of wildflowers in your favorite pastel colors . . as you approach the flowers you begin to smell their fragrance . . . you take a deep breath of the spring air , inhale . . . exhale . . . inhale . . . exhale. . . near the flowers there is a thick comforter on the ground with several pillows . . . you lie down, surrounded by the warmth of the sun and the fragrance of the flowers. . . breathe deeply, inhale, exhale, inhale, exhale . . feel the soft comforter on your skin . . . now slowly open your eyes, take another deep breath.

In a still quiet, relaxed voice, close the program by thanking the caregivers for coming and indicating that they are welcome to stay on the mats and relax for as long as they want. The caregivers who do start to get up will probably do so quietly and in this way the group will eventually break its own mood, rather than you doing so abruptly by turning on the lights.

SUMMARY FOR PRESENTATION ON MODULE #8
ON
FAMILY INTERACTIONS AND EMOTIONS

GOALS
- Look objectively at family relationships
- Help caregivers recognize emotions
- Explore constructive ways of dealing with emotions
- Stress the need for relaxation

EMOTIONS
- Care recipient feeling isolated or ignored
- Caregiver and care recipient isolated
- Caregiver feeling guilty, angry, resentful, anxious

Communication between caregiver and care recipient
- If care recipient is hard of hearing
    - Techniques to enhance communication

- Sense of touch

- Communication with other family members
    - Family in the household or nearby
    - Family far away
        - If they want to help
        - If they don't want to help

- Relationship between caregiver and care recipient
    - Present relationship similar to the past
    - Role reversal is difficult for both parties
    - Dealing with sexual relationship
    - Dealing with personality changes

- Relationship with home health aide

Emotions of care recipient and caregiver
- Distribute "How Is Your Care Recipient Feeling?"

- Distribute "How Are You Feeling?"

Bring "Home Is..." to a close
- Share joys and concerns about caregiving
- Distribute evaluation forms
- Logistics for optional module #9
- Demonstrate relaxation technique

OPTIONAL BOOKLETS FOR USE IN THIS PROGRAM

Included in this program kit are free booklets you may want to order for your caregiver participants.

FREE from: AARP Fulfillment
1909 K Street, N.W.
Washington, DC 20049

Home Is Where the Care Is - Community Resources (stock #D12954)

Order this booklet if your community does not have a community resource booklet already in existence. On your master copy of this booklet write in the pertinent local phone numbers. The caregivers in the class can fill in the numbers as each resource is explained during Module #2.

Home Is Where the Care Is - Additional Resources (stock #D12955)

This booklet lists excellent resources, many of them free, for the caregiver who has the time and desire to look into caregiving subjects in more depth. The booklet is designed as a complement to the "Home Is Where the Care Is" course. It is suggested as a handout to locate more resources rather than inundating the caregiver with actual resources that he or she may feel guilty about not using.

AARP Books brochure (stock #D12088)

Some of the resources listed in the "Home Is Where the Care Is" Additional Resources booklet are AARP books. This brochure simply gives complete descriptions and ordering information on the books. You may want to order this brochure if you use the Additional Resources booklet.

NOTE: The "The Home Is Where the Care Is" Community Resources and Additional Resources booklets contain references to an audio cassette tape (for example, "Now return to the tape"). The references exist because the booklets are also used as part of an AARP audio cassette program of the same name. You may ignore all references to the audio cassette program.

FREE from:

Dept. M. B. Woods
Consumer Information Center
Pueblo, CO 81009

Consumer Information Center catalog

Several Consumer Information Center booklets from this federal government resource are listed in the "Home Is Where the Care Is" Additional Resources booklet along with specific ordering information. The entire Consumer Information Center catalog is available for caregiver participants by writing to the above address.

The Women's Initiative is the major effort of the American Association of Retired Persons to strengthen and enlarge the leadership roles held by women; to address the special health, financial, and social needs of mid-life and older women; to create additional opportunities for women to realize their full potential; and to focus attention on the contributions women are making to society.

Because women are the majority of nursing home residents, are most often the caregivers, and because the majority of employees in institutions and agencies providing long-term care services are women, AARP's long-term care efforts are the responsibility of the Women's Initiative.

To find out how you can get involved, or to request any of our publications, write:

AARP
American Association of Retired Persons
1909 K Street, N.W., Washington, DC 20049